OPTIONS TO MEET THE FUTURE NEEDS OF CONSUMERS IN DEVELOPMENTAL CENTERS

JUNE 2002

California Health and Human Services Agency
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This report is submitted to fulfill the mandate requirement in, AB 2877 (Thomson), Chapter 93, Statutes of 2000, Section 104 (d)

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Attachments

I. PURPOSE AND ORGANIZATION OF REPORT

PURPOSE

This report is being written in response to the requirements of the Legislature as expressed in AB 2877 (Thomson), Chapter 93, Statutes of 2000, Section 104 (d), which states:

a) The State Department of Developmental Services shall identify a range of options to meet the future needs of individuals currently served, or who will need services similar to those provided, in state developmental centers (DCs).

b) The department shall establish a workgroup consisting of system stakeholders to assist in examining the various options including, but not limited to, renovation of existing DCs, smaller state owned and operated facilities, state operated leased facilities, privately owned and operated facilities, and services and supports provided in consumer owned or leased homes.

c) Options shall be evaluated for their appropriateness in meeting consumers' needs, compliance with the requirements of federal and state laws, and efficient use of state and federal funds.

d) The department shall report on these options and the recommendations of the workgroup to the Legislature by March 1, 2001.

The specific purposes of this report are to:

- Present conclusions of the stakeholder workgroup;
- Identify and describe a series of possible options; and
- Evaluate the options for their appropriateness for consumers, compliance with laws and efficient use of state and federal funds.

ORGANIZATION OF REPORT

The report is organized into the following sections:

1. Purpose and Organization of Report
2. What Options Were Considered?
3. What Criteria Were Used to Evaluate the Options?
4. Analysis of Each Option
5. Conclusions

METHODS USED

The Department used a variety of methods to collect the information needed for this report. These included:

- **Establishing and meeting with an Advisory Committee.** The Department created a broad-based Advisory Committee of stakeholders to help envision what the future of state-operated services in California would look like. The Advisory Committee on the Future of Developmental Center Services consists of all major stakeholder groups, including: consumers, parents of DC clients, parents of individuals living in the community, advocacy organizations, Legislative staff, regional centers, and community service provider organizations. In addition to the stakeholders, the Department sought input from state employee unions, representatives of the state licensing and regulatory agencies, and DC staff.

- **Obtaining information about the approaches other states used in developing community-based options for persons who used to live in their DCs.** At the request of the Advisory Committee this included visiting a limited number of other states, which had developed state-operated community services.

- **Contracting with Poindexter Consulting.** This contractor gathered, through the use of focus group sessions and interviews, information and opinions about various options from the stakeholders.

- **Contracting with George Braddock of Creative Housing Solutions**. This consultant advised the Department and others on housing issues, especially the design characteristics required in homes for consumers with various kinds of needs.

II. WHAT OPTIONS WERE CONSIDERED?

OVERVIEW

Based on what had been learned from the literature review, visits to other states, and suggestions by members of the Advisory Committee the Department drafted a preliminary list of options for use by the consultant who was assessing stakeholders' opinions. These options were included in the written material that the consultant handed out at the focus group sessions and interviews with stakeholders throughout the State. Respondents were asked to indicate whether the options were viable and whether there were additional options that should be considered.

Options included the range of residential options and non-residential services identified by the Advisory Committee and focus groups. These included daytime activities, since what a person does during the day also has to be considered in planning for his or her future, and several special services that are now or could be provided by the State in the future. In the following, we describe each option that resulted from this process of obtaining stakeholder input. The reasons for including each option also are presented.

RESIDENTIAL OPTIONS

1. Renovate and/or rebuild all five developmental centers.

This option is included in the Trailer Bill Language that instructs the Department to identify and evaluate a list of options and prepare a report to the Legislature. It was not included in the list of options that was presented to the stakeholders, but was discussed at length by many of the stakeholder groups.

2. Build new facilities on the grounds of some of the developmental centers for a limited number of consumers with severe behavioral or medical challenges.

This model was asked about in the interviews and focus group sessions, but it was not on the original list of options. It was included because some families of current DC residents thought that some consumers needed a safe setting with readily available services, stability, and increased accountability.

3. **Lease additional moderate-sized facilities in various areas of the state such as was done with Sierra Vista and Canyon Springs.** This option would identify private facilities in various parts of the State and lease those facilities for a segment of the DC population. At Sierra Vista and Canyon Springs, buildings that had been licensed as acute psychiatric facilities were leased and modified to make them appropriate for use by the Department for persons with severe behavior challenges. The facilities are staffed by State employees using staffing patterns similar to those used in DC residences of comparable size and complexity.

4. **Create State-leased and State-operated small homes in the consumers home community (for four or fewer people) for selected individuals with especially intense service needs**. Under this option, the State would establish long-term (20 years) leases with nonprofit agencies, which would build or renovate the homes to the State's specifications. These specifications would relate to the clinical and environmental needs of the people who will live there, as determined by extensive assessment. The homes would be staffed by State employees using staffing patterns that are appropriate for the needs of the consumers who live in the homes. This approach (as well as 5 & 6 below) has been used successfully in other states to reduce the size of their DC populations.

5. **State-owned and state-operated small homes in consumers' home community (for four or fewer people) for selected individuals with especially intense service needs**. In this option, the State would own the land and building, and State staff would provide services. As with the state-leased option, staffing patterns would be sufficient to meet the needs of the specific individuals served in the home.

   This option was added because of concerns from DC parents that option 4 did not provide the long-term commitment that state ownership would provide.

6. **State-owned and privately operated small homes in community.** In this option, the State owns the home and contracts with a private agency to provide services to consumers. The private agency can be removed for non-compliance with contract provisions while the affected consumers will not have to leave their home. A variation on this option would be to have the property owned by a non-profit organization such as a housing coalition.

7. **Privately operated home in the community.** In this option services and supports are provided by the private sector through regional center vendors and others.

   Although this option was not included in the original list, many community representatives thought that the private sector could serve almost all individuals who currently reside in the DCs. Adequate compensation for private providers was raised as a concern for this option.

8. **State provides special supports to privately owned and operated home.** In this option, a private vendor operates the service using private-sector staff. These private staff could be supplemented by State employees from the DCs. Services and supports provided by State staff could be management, training of direct care workers, quality assurance, or specific services and supports for individuals with special needs (behavior training programs, vocational programs, etc.).

9. **Person lives with family; state provides services.** In this option the consumer would live with a member of his or her family, with the State providing the individual services necessary to maintain that living arrangement. State services could include renovations/adaptations to the home, special supports for the person such as behavior training, and special services for the family (e.g., respite, training, support groups).

10. **Supported living or person owns own home; state provides services.** In this option the consumer lives independently, renting or possibly owning his or her own home, while individual support services are provided by State employees. State services could include overseeing direct service workers who provide direct support, or providing specialized direct services of some kind.

11. **Host (adult foster) homes for one or two consumers; homes owned by current or former State staff.** In this option, former or current DC staff open their home to one or two consumers and provide services needed in the homelike environment. This option would be similar to the Adult & Family Home Agency Model for DC consumers.

12. **Self-Determination model: state provides funds, person/family decides how to use funds, state monitors.** In this service model, individuals or their families are given a set amount of funding with which to purchase any services they think they need from whatever source they can find. Self-determination models are

now being pilot-tested in a few regional centers in California. An option for DC restructuring related to self-determination would have state staff oversee and monitor the services received by consumers included in self-determination models.

DAY ACTIVITY OPTIONS

1. **Use existing day activity and work options vendored by regional center and/or the Department of Rehabilitation (DOR)**. Under this option, consumers would participate in regular regional center vendored day programs (activity centers, adult development centers, etc.) or work settings (supported work, sheltered workshops, etc.) funded by the DOR. This option assumes that consumers are living in various community-based settings rather than on the grounds of the DCs.

2. **Use existing day activity and work options vendored by regional center/DOR; state residential staff accompany consumer.** Under this option, consumers would attend the same services as in option 1 but staff from the residential setting would accompany the consumer to provide additional support.

3. **State provides day activity and work options**. With this option, the State would establish daytime activities services, staffed by State employees. This option would only be for persons who are rejected from private day or work programs because of behavioral or medical issues. The State currently operates various daytime activities on the grounds of the DC as well as some offsite programs attended by DC residents.

4. **Individuals decide what they want to do during the day.** With this option, individuals would not be required to attend a formal day program or work setting. Rather, each person would decide what he or she preferred to do during the day.

5. **Several state-operated residences get together to design and implement day activities for their people.** This option, designed for people who would be living in some kind of state-operated residential service, would be free-form, with staff from the residences using their knowledge of the consumers and their preferences to design activities specific to the individuals' needs and desires.

6. **Individual state-operated residence designs and implements day activities for each individual who lives there.** This option again relates to persons living in some kind of state-involved residence. Under this option, staff and consumers

in a given home would design the day activities that they find the most appropriate and congenial.

OTHER STATE SERVICES OPTIONS

1. **State Regional Resource Centers:** Regionally placed centers or clinics out of which State professional staff such as physicians, psychologists, behaviorists, adaptive equipment modifiers, etc. would work. Initially, these professionals would serve the people who live in the state-operated homes in the community. Over time, the centers will become vendored by the regional centers and these professionals will serve persons with developmental disabilities who live in other kinds of settings as well.

2. **Crisis Homes:** Residences where persons in behavioral crisis can go, when in-home services have been ineffective, to receive intensive services to stabilize behaviors before returning the consumers to their regular home environments.

3. **Crisis Intervention Teams:** Teams of psychologists, behaviorists and others who could respond to requests from residential service providers, day programs, schools, or families to deal with a person's challenging behaviors.

4. **Respite Beds:** Residences that could be used for out-of-home respite for people who left the DC to live with their families.

5. **Other Suggestions for Department Initiatives:** In addition, people suggested that the Department take a leadership role in addressing some of the long-standing problems in the system. This would include:

   - Addressing the nursing shortage.

   - Operating a training academy that could bring together nationwide experts to develop curricula and to provide follow-up mentoring.

   - Recruiting highly skilled and respected professional groups to enhance our understanding of why adolescents and others exhibit severe behaviors. These groups also would participate in multi-disciplinary assessment teams to act as resources in figuring out the best approach to take with these consumers.

III. WHAT CRITERIA WERE USED TO EVALUATE THE OPTIONS?

DERIVATION OF CRITERIA

The Trailer Bill Language which mandated this report included the requirement that the "Options shall be evaluated for their appropriateness in meeting consumers' needs, compliance with the requirements of federal and state laws, and efficient use of state and federal funds".

Based on the comments and suggestions of the stakeholders and the work that was done by the consultants, the Department developed criteria to evaluate appropriateness.

- For the "DC Options Study", Poindexter Consulting asked participants in interviews or focus group sessions what they considered to be the most important values exemplified by the DC, and what values or principles should be seen as the most important in developing future plans for DC services.

- Creative Housing Solutions outlined the importance of criteria related to matching a person with his or her environment.

The list of criteria included elements from each of these analyses. In identifying criteria that could be used to evaluate the options, every attempt was made to include the issues about which people expressed the strongest opinions or which appeared to be the most important to them.

Two general categories of criteria were identified. One group consisted of consumer-related issues--things that were considered vital to consumers' well-being such as the way in which people are treated or perceived. The second category consisted of criteria that are related to the system of services for people with developmental disabilities.

CRITERIA

Consumer-Related Criteria:

A. Stable, Qualified Staff: Residential settings should be stable, of high quality, and staffed by well-trained, well-paid, and compassionate people.

   This criterion was agreed to by the stakeholder groups. Nearly everyone emphasized the importance of having a stable, well-trained workforce, with staff who are knowledgeable about the needs and preferences of the persons whom they serve.

B. Integration into Community Life: Living in neighborhood communities close to family members; and participating as full members of regular communities.

   This criterion was mentioned by nearly everyone except some of the DC families. Most of the people who were interviewed saw integration into the "regular" life in the community as a fundamental right of persons with developmental disabilities as enumerated in the Lanterman Act. Stakeholders believed that integration into the community should be a major goal regardless of whether services are provided by the state system or private providers.

C. Home-Like Settings: Maximizing opportunities for individuals to live in small, home-like settings.

   Again, this criterion was mentioned primarily by persons advocating for community services. Over the years, more and more individuals with developmental disabilities in California and across the nation have been asking for, and choosing opportunities to live in, small home-like settings in their home communities.

D. Individual Home Design: Ensuring that the person's home is designed and equipped to meet his or her needs.

   This criterion is based on Mr. Braddock's demonstrations in Oregon as well as here in California that it is possible to design a person's living environment such that it maximizes the person's safety, privacy, and pursuit of preferred activities, while being safe and convenient for staff, and non-threatening to the neighbors. Including an environmental component in the individual's assessment is essential.

E. Access to Services: Ensuring that home has access to the kinds of services that are needed by the persons who live there.

This criterion was given great importance by stakeholders throughout the system. Stakeholders indicated that access to quality health care and other essential services must be guaranteed and established before individuals move into new living arrangements. Many mentioned that some method should be developed to share with the community many of the specialized services and supports provided by the DCs to their own residents--e.g., medical, dental, physical therapy, adaptive equipment, behavior intervention, pharmacology.

System-Related Criteria:

F. Limited State Role: The State's role should be as a provider of those few services that the community system is unable to provide at any given time.

Most persons who were interviewed felt that there should be no attempt to duplicate services offered by the private sector, or to set up a parallel system of comparable State services to serve a wide range of individuals with developmental disabilities. Stakeholders thought the State should be involved in direct services only for those limited groups of individuals whose extremely complex needs exceed the private sector's resources or expertise at any given time.

G. Integrate the Two-Tier System: Integrate the two-tier system that Stakeholders believe exists due to the State and private sector providing services.

Many of the persons interviewed from the community system thought that a division exists between State and private sector services, and they recommend efforts to remove this division. Some stakeholders feared that this division would be exacerbated if the State developed comparable community-based State-involved services. Others thought that there should be a more effective mechanism to determine levels of service to ensure that only persons with extremely complex needs are afford the opportunity to receive the higher intensity services such as the State might provide. Substantial effort also needs to go into expanding the capacity of the community to serve persons with these very complex needs.

H. Retain Staff Expertise: Retain the expertise of staff who work in the DCs and share it with the community.

Nearly every segment of the stakeholder group felt that it was very important to retain the expertise of the state staff who work in the DCs. Many stakeholders pointed out that highly-qualified, well-trained staff are very scarce, and that a serious workload shortage is expected in the future. This makes it even more critical that these highly-trained persons who work in the DCs not be lost as occurred with many DC staff with the closure of Stockton and Camarillo.[1] Further, most stakeholders wanted the Department to find a way to share these resources more widely than currently is possible.

Other considerations that apply to all options were:

C **Individualized Assessment:** Basing all decisions on personalized assessment, the individual's choices, and the use of individualized planning, resource development and environmental assessment.

This criterion was universally accepted by the stakeholders. Nearly every person and group stated that plans for the future of DCs must begin with a thorough assessment of each individual and his or her needs and preferences. Most stakeholders strongly recommended that a comprehensive Person-Centered Planning process be used, and many people emphasized the importance of individually designing resources to meet people's needs.

C **Uniform Quality Assurance System:** Establish a uniform quality assurance system that would apply to all types of services and supports, regardless of who provides them.

Stakeholders from many different groups felt that it was extremely important to establish a uniform quality assurance system that would apply not only to any new system of services that is created, but also to the system of private-sector services that now exist. This new system, which would be designed by the State in conjunction with the Stakeholders, would go beyond what currently is done in the area of quality assurance and should include the whole range of actions from defining standards through monitoring and follow-up systems.

[1] Staff from Stockton and Camarillo who chose not to transfer to another DC were assisted to find jobs in other state agencies or in the private sector. Very few people were laid off, but the expertise of these people was lost to the system of services for persons with developmental disabilities.

- **Accessing New Funding Sources:** Stakeholders felt that the State should do everything it possibly could to augment State funds.

  Stakeholders recommended the use of bonds for housing purposes, soliciting the involvement of housing development corporations, or maximizing federal funding opportunities such as expanding the Home and Community Based Waiver, and using Medicaid funds for case management during the placement process.

IV. ANALYSIS OF EACH OPTION

INTRODUCTION

In the prior two chapters we have identified the list of options for future DC services and presented the criteria that will be used to evaluate especially the residential options. These options and criteria were developed based on the input from stakeholders and consultants.

In this chapter, we discuss each residential option and review it in terms of the criteria that have just been discussed.

RESIDENTIAL OPTIONS

1. Rebuild all DCs.

This option was the favored option of families of current DC residents. Some of these family members suggested that the expenditure of additional dollars to rebuild and renovate the DCs would be manageable if it was spread over 10 years or so. Others were not sure that the dollar amounts presented in the Vanir report were accurate or that it would cost nearly that much to renovate or replace the DCs.

Other than the subset of DC families, this option was not considered feasible or desirable by the rest of the stakeholders. Many stakeholders felt that the funds required to make modifications to the existing buildings could and should be utilized to fund other options, especially those that would expand and augment the capacity of the community to serve and support people with developmental disabilities.

This option meets the criteria related to stable and qualified staff (A) and retaining staff expertise (H) since all persons and staff could be expected to remain at the DCs. For similar reasons, it also meets the consumer-related criterion of access to needed services (E).

TABLE V-1: RESIDENTIAL OPTIONS JUDGED AGAINST CRITERIA

OPTIONS	A Stable, qualified staff	B Integration in community	C Home-like setting	D Individual home design	E Access to services	F Limited State role	G Integrate Two-Tier System	H Retain staff expertise
1. Rebuild all DCs	X				X			X
2. Build new on grounds of some DCs	X		X	X		X		X
3. Lease moderate-sized facilities	X							X
4. State-leased & state-operated small	X	X	X	X	X	X		X
5. State-owned & state-operated small	X	X	X	X	X	X		X
6.State-owned & privately operated small		X	X	X	X	X	X	
7. Privately operated		X	X	X	X	X	X	
8. Private home with state supports	X	X	X	X	X			X
9. Person lives with family, state supports	X	X	X	X	X			X
10. Supported living, own home, state supports	X	X	X	X	X			X
11. Host homes, state supports	X	X	X	X	X			X
12. Self-Determination; state supports		X	X	X	X	X		

This option did not meet criteria B (integration in the community, criteria C (homelike setting), or criteria G (diminish the perceived two-tiered system).

2. Build new facilities on the grounds of some of the developmental centers for a limited number of consumers with severe behavioral or medical challenges.

This model was not on the original list of options but was raised in the interviews and focus group sessions. Most families of current DC residents preferred the congregate nature of the DCs with their readily-available services, stability, and accountability. However, it was strongly rejected by community-based stakeholders.

Based on the evaluation criteria, this option:

- Supports the stakeholder criteria that the role of the State is to provide services in situations that appear to be beyond the expertise or willingness of the private sector (F);

- Entails building new homes that could be designed to meet the needs of relatively small groups of individuals (B) and these homes could be designed to exhibit “home-like” features (C);

- Retains the expertise of DC staff (H) and meets the criterion of stable, qualified staff (A); and

- Will not diminish the complaint about the perceived two-tiered system (G), even though only a small number of individuals would be served in these settings.

- Does not meet the criterion of community integration (B) because the new residences would be located on DC campuses rather than in community settings.

3. Lease additional moderate-sized facilities in various areas of the state such as was done with Sierra Vista and Canyon Springs.

This option was discussed by some of the stakeholders, but it was not acceptable to most. DC families wanted to retain the DCs because of the services they provide and they feel that the whole community nature of the DCs keeps their relatives safe from abuse and devaluation by members of the community. DC families do not believe a 60-bed facility in the community would provide the same level of safety. Community stakeholders rejected this option because of the size of the proposed facilities. Both Sierra Vista and Canyon Springs can provide services for about 60 individuals. While community stakeholders can understand the population pressures that led the Department to develop these leased facilities, it is not a model that they would support as a viable future option. In their view, leasing places in which up to 60 individuals will live is merely trading one institution for another and, as such, they see this as in violation of both the spirit of Olmstead and the Lanterman Act.

This option also does not meet the criteria related to community integration, home like settings or individual home design (B-D), nor is it a method of reducing the two-tier problem (G).

On the positive side, this option does retain State staff expertise (H) and provide qualified and stable staff (A).

4. State-leased and state-operated small homes in the consumers home community (for four or fewer people) for selected individuals with especially intense service needs.

DC parents were the major group who objected to the small size of these homes. They thought the homes would be too isolated from other similar homes, that medical and other services would be difficult to obtain, and that their relatives were used to the larger institutional environments. In addition, some community respondents suggested that the economics of the small homes could be a barrier. DC families also objected to the idea of leasing the property, rather than owning it, because they thought even a long-term lease would not provide the kind of long-term commitment that they expected of the State.

Many community respondents pointed out that working in a small home requires staff to be more “full-service” than a DC -- cooking, cleaning, household chores that are done by others in a DC -- and that staff would have to exercise more independent judgment in a small home. These people suggested that a well thought out and constructed training plan would be needed to help people make the transition. Other states that have created state-operated community options also strongly emphasized the need to provide training for the staff who move out of DCs. This model of small homes also has been found to be effective in moderating and improving the challenging behaviors displayed by the individuals who live there. (See Attachment 2 for a discussion of the positive impacts of small state-operated settings in other states.)

Some respondents have suggested that this option could be expensive. If the home was for four persons with intense behavioral or medical needs, using staffing patterns that are now employed in the DCs, the annual per capita expenditures for this option would exceed the average cost of a DC. Using slightly larger models and/or somewhat different staffing categories may improve the efficiency.

This option meets most of the consumer-related criteria. It uses State staff, so it ensures stable and qualified staff (A) and retains the expertise of State staff (H); it would be located in a regular community so persons would have the opportunity to participate in the life of the community (B); it would be designed to be both homelike (C) and to meet the special needs and requirements of both consumers and staff (D); it would be located in communities with good access to needed services (E).

Because of the two-tier issue (G) as well as the expense, it would be necessary to develop careful definitions of levels of service that the State would provide in these homes if this option were implemented. Strong criteria that would limit the State’s role to those the community cannot serve at any given time would have to be established (F).

5. State-owned and state-operated small homes in the community (for four people or fewer) for selected persons with especially intense service needs.

The evaluation of this option is identical to the one above except the only difference would be whether the State owned or leased the property on which the home would be located.

6. State-owned and privately operated small homes in community.

This option was viewed by the community stakeholders as providing a long-term state commitment to the system of services through ownership of the property. They also saw it as having a positive impact on quality through the assurance that inadequate service providers can be removed if necessary (A). This model also could be created to meet the criteria of integration into home communities, a home-like setting, and even a design that reflects the needs of the persons who will live there (B, C, D). The homes also could be sited in towns or communities with good access to the services that people will need (E). It could assist with the two-tier issue because it would not involve State staff competing with private providers. State ownership of the property also could make it easier to acquire service providers in high-cost areas as these people would be responsible for only the service and supports portion of the budget.

This option has the disadvantage of not making use of the DC staff expertise (H) and that there may not be sufficient high-quality private sector staff to work with people with extensive service needs (A). The community liked this option, primarily for people with very extreme needs. This option could result in higher costs as stakeholders believe that residential rates would have to be augmented to make this work.

7. Non-profit owned and privately operated small homes in community.

This is a variation on the state-owned and privately operated option. Under this option, a non-profit organization such as a housing coalition would own the home, while services would be provided by a private vendor.

The analysis of this option regarding the criteria is the same as for Option 6. It has the advantage of allowing the separation of the direct service portion of the operation from the home ownership component. This makes it possible to replace an inadequate service provider without relocating the individuals who live in the home.

This option has the same disadvantages that were identified for option 6.

8. Privately owned and operated homes in community.

This option, as with option 7, was supported by many advocates for community living, especially those who thought that the State should not get involved in providing community-based services in competition with the private sector.

Rather, these persons suggested efforts should be made to upgrade the quality and knowledge of community staff so that they would be more capable of providing supports and services to persons with intense needs. Most people thought that private providers could provide services for many of the persons now living in a DC, but that extra planning and resources would be needed for persons with extremely challenging needs.

In terms of the criteria, the State and the regional centers could select only providers who were willing to create homes that met the integration, home-like, and individual-design criteria (B-D), and that are located with appropriate access to services (E). This option also would serve to limit the State's role (F) and the two-tier problem (G), depending upon the proportion of the population that the private sector could be prepared to serve.

This option would not meet the criterion of stable and well qualified staff (A) unless State requirements were created to make this option more feasible. Stakeholders believe it will take a system rate increase to make it a viable option. It would not meet the criterion of retaining the expertise of the State staff who now works in the DCs (H).

9. State provides special supports to privately owned and operated home.

Community-based individuals tended to like this option, although some pointed out that the relationship between the private owner and the State staff would have to be worked out carefully and others were a bit leery of the State's involvement in the private sector system of services. Such a private-public partnership has worked well for several years with the crisis homes for children in the communities of Porterville and Stockton. In crisis homes, State staff supplement the private staff and, in the process of so doing, teach the private staff how to deal with persons with serious behavioral issues. A similar private-public partnership has been used with the transition homes that Inland Regional Center developed in conjunction with Canyon Springs. (These homes also will be the first demonstration of the benefits of homes designed specifically around the needs of the persons who will live there.)

Basically, this option has all of the advantages of option 7 above, plus it would make use of the staff who now work in the DCs (H). This option also provides reassurance that expert staff will be available to support persons with very difficult needs (A).

10. Person lives with family; state provides services.

This option was not favored by DC families, who thought they were too old to take their relatives home, though they thought it might work for younger families. Some community stakeholders questioned why the state would create this option when similar supports already are provided by the regional centers.

This option, and the other "individualized" options that follow, has the advantage of using State staff (H) to ensure that stable and well-qualified staff will provide services for those persons who wish to live with their families (A). Such arrangements are certainly home-like and integrated into regular communities (B and C). The State-funded home adaptations that may be part of this model should create environments that meet the needs of the individuals who live there (D). State staff would provide or ensure access to needed services under this option (E).

11. Supported living or person owns own home; State provides services.

Although this option was widely supported as a service model by the community, it was not supported as a State service. DC families think their relatives are too impaired for supported living. As with the prior option, community stakeholders thought this option would best be provided by the private sector.

If it were to be decided that this would be a beneficial option for some portion of the population, perhaps those with extraordinary needs, it could be implemented with State staff in either an oversight capacity or providing direct services for a selected group whose needs preclude less, well-trained service providers. As such, it would meet the criteria of stable, qualified staff (A) and retaining the expertise of State staff (H). Supported living meets the criteria for a home in an integrated setting B and C), and homes would certainly be designed to meet the needs of those who live there (D). As with the prior option, Stakeholders believe the involvement of State staff would help with the issue of access to appropriate services, either by providing those services or by working with the regional center and community agencies to ensure that necessary services are available (E).

12. Host (adult foster) homes for one or two consumers; homes owned by current or former State staff.

This option is widely used in Colorado, where it has had the advantage of retaining the expertise of DC staff and expanding the range of community services.

This option was neither favored nor disfavored by the stakeholders. People pointed out that California has not been very successful in developing adult family homes which are a similar service model. They also thought that something would have to be done to change the regulations to permit State staff to offer such services as State employees, or to retire and immediately open a host home. As with the prior individualized options, this option meets most of the criteria on the list (B, C D, E, H).

13. Self-Determination model: State provides funds, person/family decides how to use, state monitors.

As with supported living, self-determination service models are rated very highly by persons from the community, but most people thought that the State's involvement in self-determination should be limited to encouragement, facilitation, and funding. It is difficult to assess this option against the criteria because the individuals themselves would determine what they wanted and who should provide it to them.

This option meets most of the community-based criteria (B, C, D, and E) and the criteria for individualized assessment as consumers and/or their families would be involved in determining their own services and supports.

DAY ACTIVITY OPTIONS

Generally, fewer comments were received on Day Activity options than residential ones.

1. Use existing day activity and work options vendored by regional center and/or the Department of Rehabilitation (DOR).

This option was preferred by most of the stakeholders who commented on the day activity options. Stakeholders thought that the State should not get involved with day activity options. Most persons thought the private sector--regional center vendors or services funded through the DOR --could develop sufficient day programs to meet the needs of persons who might chose to leave DCs.

2. Use existing day activity and work options vendored by regional center/DOR; State residential staff accompany consumer.

Stakeholders did see the utility of having State staff participate in day services for persons with extremely challenging needs. This would not necessarily be residential staff but could be State staff assigned especially to this service model.

3. **State provides day activity and work options.**

   As was mentioned above, stakeholders were not enthusiastic about having State staff provide day or work services.

4. **Individuals decide what they want to do during the day.**

   This option is gaining more support from some of the stakeholders as consumers and families are seeking greater flexibility in making decisions on the types of services they receive. However, some form of structured day activities are considered essential by many of the stakeholders to prevent isolation, provide social opportunities, and create an additional quality assurance mechanism.

5. **Several state-operated residences get together to design and implement day activities for their people. Individual state-operated residence designs and implements own day activities for each individual who lives there.**

   The stakeholders rejected the idea that residential homes, whether State- or privately-operated, should offer day programs. Stakeholders felt that individuals should have an opportunity to leave their residence and to have staff other than those providing residential services observing and interacting with them each day.

OTHER STATE SERVICES

1. **State Regional Resource Centers**: Regionally placed centers or clinics out of where State professional staff such as physicians, psychologists, behaviorists, adaptive equipment modifiers, etc. would work. These professionals would serve the people who live in various residential settings in the community.

   DC families refer to this idea as “Centers of Excellence” and it was supported by these families as well as by persons in the community sector. Community advocates wanted these services to be available immediately to people living in the community as well as to those who chose to move out of the DCs. Some regional center staff thought that these clinics should be attached to them rather than operated by the State. People gave various suggestions as to how these resources could be spread around the State. This included video technology, telemedicine, mobile teams, apprentice programs and so forth.

Interestingly, various respondents mentioned other ways in which the State could provide services to augment the system, and most of these are compatible with the idea of area clinics or service centers. Among these ideas are:

- A place in the community that could review, supervise and control psychotropic medications.

- A short-term treatment and rehabilitation facility for people with challenging behaviors or mental health issues.

- Psychiatric centers to work with adults.

- Teams of psychologists, behaviorists and others who could respond to requests from residential service providers, day programs, schools, or families to provide intensive crisis services to persons with challenging behaviors.

- A location that could be used for out-of-home respite for the people who left the DC to live with their families or in other individualized or family-like settings.

2. **Crisis Homes**: Residences where persons in behavioral crisis can go, when in-home services have been ineffective. Individuals would receive intensive services to help manage their behaviors and regain control before returning to their regular home environments. Crisis homes that have been established as joint ventures among the State, regional center, and the private sectors have been successful in helping individuals to manage their behaviors. Stakeholders thought that more of these should be created and that crisis home staff could also provide training to regular care providers.

MANDATORY PLANNING ELEMENTS

Regardless of the options that are selected, the Department has identified trends in the stakeholder and consultant input that it considers to be mandatory in the implementation of options. These are essential considerations for designing new options for persons living in, or having a potential for living in, a DC. Some of these are imbedded in the consumer-related criteria that have been discussed. Others were reflected in the values that were expressed by the stakeholders in the Poindexter surveys. Still others were identified either in the findings from our visits to other states or in the research literature.

These are all summarized in Table V-3. This table also lists the major activities that must be undertaken to ensure that the values are given explicit attention and accomplished during the planning process.

Regardless of the types of options that eventually are selected, it is essential that the values and actions outlined in Table V-3 be a basic part of the planning process.

TABLE V-3: ESSENTIAL COMPONENTS OF PLANNING FOR AN INDIVIDUAL'S NEW HOME		
RELATED TO:	**VALUE**	**HOW WILL ACCOMPLISH**
Consumer	1. Safety, Freedom from Abuse; 2. Treated with Dignity, Respect; 3. Encouraged in Independence; 4. Encouraged in Productivity; 5. Choice, Control, Empowerment; 6. Full Participant in Community; 7. Acceptance by Community.	8. Staff training on values; 9. Design of service and supports; 10. Outcome measures for values; 11. Reporting systems; 12. Incident reports; 13. Unannounced visits by staff, parents, others; 14. Work with neighbors and community on integration.
Staff Quality	15. Staff trained, qualified to meet needs.	16. Selection criteria and training requirements for staff. 17. Appropriate staff compensation.
Home	18. Maintain current friendships after move; live with whom one wants.	19. Selection criteria regarding people with whom consumer lives.
	20. Home meets consumer=s needs and preferences; 21. Home meets essential health and safety requirements; 22. Home meets core values of being homelike, non-	23. Home design: adapt or modify prototypical home models based on needs. 24. Layout, materials and equipment. 25. Small size of home, amenities.
	26. Close to family, outside friends; 27. Close to necessary services such as health care; 28. In a regular neighborhood, part of larger community.	29. Siting of home in neighborhood, community; 30. Blends in with (looks like) other houses; 31. Work with staff to minimize neighbors' concerns.
Services & Supports	32. Meet consumer's needs and preferences; 33. Change as consumer's needs and preferences do; 34. Someone knowledgeable to help consumer/family find services, supports and options; 35. Special attention to access to vital services such as health care, specialists, etc.	36. Comprehensive Assessment and Person-Centered Planning to identify service, support, and environmental needs. 37. RC case manager/service coordinator to find services and supports, evaluate, and change.

EFFICIENCY IN THE USE OF STATE AND FEDERAL FUNDS

Efficiency in the use of state and federal funds is important at any time, and especially when the state's resources are constrained. Efficiency is most often thought of as cost-effectiveness, and in the present instance, a common misstep would be to ask whether the costs of the various community living options are more or less expensive than the cost of a developmental center placement. This leads to the misconception that if a placement was less expensive, it could be considered cost-effective.

The foregoing form of analysis is problematic when evaluating the community placement of persons with developmental disabilities. This is because each individual is unique, particularly persons who have required the sophisticated care that currently is most often provided in a developmental center. Consequently, different individuals will cost different amounts when placed into the community, even when placed in the same living option.

Similarly, the costs of caring for different individuals in developmental centers varies widely. While one can mathematically calculate the average cost of serving all the individuals in a developmental center, this average cannot be used to determine whether or not it is cost-effective to place a given individual in a community home. For example, if the average cost per resident of a developmental center is $150,000, and a community living plan appropriate for that individual costs $180,000, one could conclude that making such a placement is not cost-effective. However, it may well be that the cost of serving that particular individual in the developmental center is actually $200,000, so that placement would indeed be cost effective.

In short, it is not possible to state that any of the living options identified in this report are or are not an efficient use of public funds. What is fair to say is that each of the options is likely to be cost effective for some individuals, while none of the options is likely to be cost effective for all individuals. In making placements, therefore, the most efficient use of public funds is likely to be achieved by utilizing a mix of options. With multiple options available, individual assessments of necessary supports and services for each person must be completed and compared to the resources available at the moment to identify the most cost-efficient living situation that meets an individual consumer's needs.

Over the past decade, the Department of Developmental Services has increasingly focused on placing individuals into community homes. During the past six years, the Department and Regional Centers have placed more than 6,000 individuals in

community living situations. The policy of placing individuals into community homes, and not developmental centers, has been and continues to be firmly established at the Department.

In the new Community Placement Plan process, the Administration has put forward the means by which the regional centers will be able to conduct individual assessments and to develop community living options that meet the needs of developmental center residents who face exceptional challenges.

CURRENT POLICY INITIATIVES AND ACTIVITIES

Any policy discussion regarding the future uses of developmental centers and the best options for the DC population, should take into account the activities currently underway to build community capacity, strengthen the quality and stability of community services and maintain the structural integrity of the DCs while they continue to be used. The following departmental initiatives have been designed specifically to address some of the concerns and barriers posed by the stakeholders.

1. New Community Placement Plan Process

In response to the U.S. Supreme Court's decision in *Olmstead v. L.C.*, and the resulting planning principles articulated by the Centers for Medicaid and Medicare Services, the department re-conceptualized its community placement plan (CPP) process. The new policies contain all of the following:

- **Individualized Planning**

The regional centers are required to conduct individualized, person-centered planning based upon a comprehensive assessment of each individual.

- **Collaboration**

CPP policies include a definition of the roles of the responsible entities, including regional centers, developmental centers and regional resource development projects, and the Department's expectation of full cooperation among these entities. The policies also emphasize the active involvement of the consumer and his or her family in the decision-making process.

- **Resource Development**

Funding is provided to develop new community services and supports, as indicated by the individualized assessments **.** Resource development includes funding both for the start-up of new resources as well as for the staffing needed to solicit providers and guide them through the process.

- **Deflection**

Funding is also provided to prevent admissions to developmental centers of individuals whose community placements are in jeopardy**.** Regional Centers must identify those individuals who have been referred to regional resource development projects and must specify the unanticipated services and supports, not already included in budget trends, that the individuals need to stabilize their community living situations.

- **Transition**

Transition includes those activities conducted by the regional center, the developmental center or the regional resource development project to prepare the consumer to exit the developmental center and adjust to a new living arrangement in the community. This may include information such as videos as well as visits and overnight stays at the community facility.

- **Quality Assurance**

Regional center plans may also include additional staffing for quality assurance activities to ensure that the individual has adjusted to the new living arrangement, is receiving the services specified in the individual program plan, and is not subject to adverse circumstances that could jeopardize the placement.

- **Performance and Accountability**

At the end of the year, each regional center's performance is assessed in light of the goals of their plans. Future year's plans and budget allocations will be adjusted based upon performance.

2. QUALITY INITIATIVES

All discussions regarding the future of developmental centers have emphasized the necessity of building a quality, stable community service system which has the capacity to ensure the individual's health, safety and well-being. Two issues have emerged over the last few years as significant concerns: (a) access to health, mental health and dental services and (b) the management and mitigation of risk, including health and safety. The department has developed specific responses to these concerns: the Wellness Initiative and the Risk Management and Mitigation System.

- **Wellness Initiative**

The primary focus of the Wellness initiative has been to assist consumers in accessing quality medical, dental and mental health services by increasing the knowledge and capacity of health care providers. Due to wellness initiative funding, over 4,500 consumers with complex health problems have received targeted services, over 2,600 health professionals have received training on health issues specific to persons with developmental disabilities, and over 36 partnerships have been developed with university medical and dental schools, state organizations, professional associations and service agencies. Systems for outreach, training and consultation have been developed, including a professional website (www.ddhealthinfo.org), a free consulting

service for physicians (PACTnet), and professionally developed materials (Wellness Digest, Health Notes: Care of Children and Adults with Developmental Disabilities). The activities conducted under the Wellness Initiative are flexible and dynamic, capable of responding quickly to identified needs. As such, it represents a significant resource for developing community capacity in the health care arena.

- **Risk Management and Mitigation**

The department developed a risk management and mitigation system in response to concerns by the Centers for Medicaid and Medicare Services over inadequate systems to monitor and protect consumer health and safety. The new multi-level system is designed to report, track and ultimately reduce consumer abuse, exploitation, neglect, illness, injury and death. The system includes an automated special incident reporting system that provides for statewide and local trend analysis and mitigation planning. An independent contractor provides risk management training, data analysis, information dissemination, mortality reviews and prevention planning.

3. ENHANCING FEDERAL FINANCIAL PARTICIPATION

The department has launched an initiative to pursue all opportunities to enhance federal funding in order to maintain and improve the community services system. The department's goals are to ensure that the state meets its commitments to the federal government to ensure that quality services are provided under the Home and Community Based Services Waiver, to increase the State's amount of federal financial participation for existing services and future growth where such opportunities exist.

4. TARGETED RESOURCE DEVELOPMENT

The department has provided staff resources to promote the development of specific program models, one to deflect the admission of children to the developmental centers and one to facilitate the transition of behaviorally involved individuals from the DC to the community. This approach combines the expertise and resources of the state with that of the regional center in order to achieve mutual goals.

- **Children's Crisis Homes**

In partnership with regional centers, the department has spearheaded the development of specialized short-term services for children and adolescents who are experiencing an acute behavioral crisis. These specialized services are provided in 2 bed residential facilities that are operated by a regional center vendored provider with support services from a developmental center. The programs are designed to resolve an acute behavioral crisis in a small homelike environment so that the person can return to the community with the tools to prevent a similar crisis in the future. A total of 8 crisis homes have been opened throughout the state.

- **Adult Transition Homes**

Similarly, the department coordinated its resources with a regional center and a provider to develop four, 4 bed facilities designed for adults with significant behavioral needs. The program is designed as a two-year transition program which prepares consumers to live successfully in the community. During the opening phase of each home, developmental center staff who are experienced in working with the consumers were deployed at the homes to work on consumer behavioral issues and to train staff. This support is being reduced over time.

5. CAPITAL OUTLAY

The State continues to face the dilemma of balancing the need to keep aged DCs and infrastructure safe for people who live there with the current economic realities and limited resources for capital outlay projects. Some expenditures must be made; however, the department has adopted a very conservative approach to its facilities planning. Other than requests for security modifications and limited expansions to accommodate the growing forensic population and a behavioral program, the Department's only capital outlay requests in recent years have been for fire, life safety, critical infrastructure and ADA compliance. The department's objective has been to maintain minimum compliance with fire, life safety and building code requirements, to correct basic infrastructure deficiencies that are critical to the facilities' operations and to ensure continued federal certification for medicaid reimbursements.

V. CONCLUSIONS

CONCLUSIONS

There was a multitude of issues discussed by the stakeholders (consumers, parents of DC clients, parents of individuals living in the community, advocacy organizations, legislative staff, regional centers, and community service provider organizations) as they examined the various options. While there was not a consensus on all the issues, there was a preponderance view among the stakeholders' group on a number of the issues. These stakeholder views are summarized below:

A. The DCs should not be renovated. The long-range future of State-provided services should not be tied to the existing buildings or the geographic location of current campuses. The funds required to make modifications to existing structures may be better utilized to create a new service structure. The exception to this is Porterville, which everyone expects will continue indefinitely as the home for persons with forensic/severe behavior issues.

B. Because the development of new options will be a slow process, funding for physical improvements to some buildings will be needed to keep them safe and habitable until they are no longer needed.

C. There is an ongoing need for the State to provide direct services, but only as the "provider of last resort." There is little interest in having the State set up a system of services that would compete with the private sector. Rather, the State's role needs to be carefully defined as providing residential services to those whom the private sector cannot serve at any point in time.

D. State staff employed by the developmental centers are an essential component to assuring stability, quality, and continuity of services. Planning should incorporate how to best use these valuable resources.

E. Options for increasing federal financial participation and other funding streams in funding the cost of developmental services without a corresponding increase in the cost to the State should be explored. Leveraging of DC property for the sole benefit of the DD service system is a public policy issue that will continue to be debated. As programs compete for limited funding resources a determination on the level of resources to be provided should be decided through the budget process.

F. There is a serious need to strengthen and expand the capacity of the private service delivery system so that it is better able to meet the needs of persons such as those who reside in the DCs or who will need DC-type services in the future.

G. Developing high-quality community services should be a priority activity, along with designing effective methods for monitoring and assuring that quality

H. Planning must begin with the individual. A comprehensive person-by-person assessment should be the foundation for determining the array of services and supports that will be required to meet individuals' physical, service, support, and environmental needs.

I. Determining the resources that will be needed in various parts of the State can best be accomplished on an area or regional basis with the participation of the regional center(s), the DC, vendors, families, and other stakeholders. Each area should be evaluated for the services it most needs, including those that potentially could be provided by State staff.

J. Rather than recommending a single option, the stakeholders agreed that a range of different options should be developed to meet the varying needs of persons in the DCs or who have similar needs. They concluded that the State's basic policy strategy should be to balance the consumer-related and system-related criteria that have been identified.

ADVISORY COMMITTEE ON RESTRUCTURING DEVELOPMENTAL CENTER SERVICES

BACKGROUND

The Department created a broad-based Advisory Committee of stakeholders to help determine what the future of state-operated services in California would be. The Advisory Committee on the Future of Developmental Center Services consists of all major stakeholder groups, including: consumers, parents of DC clients, parents of individuals living in the community, advocacy organizations, Legislative staff, regional centers, community service provider organizations, state employee unions, representatives of state licensing and regulatory agencies, DC staff and others (see Table for member list).

FIRST MEETING

The first meeting of this group was in December 1998. The purpose of the meeting was to review the Vanir report on the condition of the DCs and to help design a process for moving forward to identify options. Nearly all of the Advisory Committee subgroups that were formed to discuss the future indicated that they did not favor rebuilding the DCs, that other kinds of state-involved service options should be considered, and that efforts should be made to create a “seamless” system. The Advisory Committee also recommended that a group travel to other states to examine the community-based, state-operated services that those states had created. At the time, 18 states had developed small, state-operated services in the community, mostly as a replacement for their large state institutions, which they were closing or downsizing.

SECOND MEETING

The second meeting of the Advisory Committee was in June 2000. Information from the visits to other states was discussed. Presentations were also made by persons who had been involved in developing the state-operated community homes in the states of Oregon and New York.

The Advisory Committee agreed to five principles/objectives to guide the study of options for DCs. The principles to which they agreed were stated in very general terms, and are shown in bold print. The meaning of each principle follows.

1. **No capital outlays to rebuild DCs.** Funds should be spent on developing other kinds of options to enhance system capacity rather than on remodeling the DCs.
2. **Homes should be limited to four or fewer persons.** Small homes are the ideal. It is recognized, however, that larger arrangements might be necessary for some groups of persons.
3. **Capture and extend DC resources into the community.** The highly skilled and committed State staff that currently serve the individuals in the DCs must be retained regardless of what DC Options are selected. They are invaluable resources, which will be essential under any new system of services. State staff could provide not only residential services, but also the full range of professional services—medical, physical therapy, psychological, etc.—they now provide in the DCs.
4. **Leverage the DC land to create new resources**. Fund the new system, to the extent possible, through selling, leasing, trading or in other ways capturing and maximizing the resources that now exist in the DC property. The majority of these resources should accrue to the developmental disabilities service system rather than to the General Fund.
5. **Conduct highly individualized personal assessments and resource development before anyone moves to the community.** Comprehensive person-centered assessments will be essential to determine what kinds of services and supports are needed and preferred by each individual. The results of these assessments should be used as part of an assessment of the resource needs in each region of the State.

After the meeting, these principles were broadly distributed across the constituency and more than 20 key organizations agreed to support them.

CONSULTANTS

With the assistance of funding provided by the Legislature in the 2000/01 budget, the Department contracted for the services of a series of consultants to assist with the DC Options project.

- Judith A. Poindexter, Consulting Services, conducted focus group sessions and interviews with stakeholders throughout the State to gather their opinions about a series of options.
- George Braddock of Creative Housing Solutions in Eugene, Oregon
- prepared a report that summarized the factors that need to be considered in maximizing the "fit" between an individual's needs and the
- characteristics of the home in which he or she lives and the community in
- which that home is located.

THIRD MEETING

The third meeting of the Advisory Committee was held in November 2000. At this meeting, Judith Poindexter presented her findings. She outlines the stakeholders' opinions about the options, and received feedback from the stakeholders on her report. After the third meeting, Ms. Poindexter conducted additional interviews and focus group sessions as requested by the Advisory Committee. She then revised her report based on this input and that of the Advisory Committee. Ms. Poindexter's report is in Attachment 3.

ADVISORY COMMITTEE ON RESTRUCTURING DEVELOPMENTAL CENTER SERVICES

Advocates	Providers
• Area Board IV • Autism Society of Los Angeles • California Alliance for Inclusive Communities • Community Advocacy Services Association, Inc. • Organization of Area Boards • People First of California • Protection and Advocacy, Inc. • The Oaks Group • State Council on Developmental Disabilities	• Association of Retarded Citizens—California • California Association of Health Facilities • California Association for the Retarded • California Coalition of United Cerebral Palsy Associations • California Rehabilitation Association • Community Residential Care Association of California • Easter Seals • Independent Options, Inc. • Society of California Care Home Operators, Inc.
Developmental Center Parent Groups	**Developmental Centers & Regional Centers**
• Association of Mentally Retarded at Agnews • Fairview Families and Friends • Advisory Board for State Agencies—Lanterman Developmental Center • Porterville Developmental Center–Parents and Friends • Sonoma Parents' Hospital Association • California Association of State Hospitals/Parents' Council for the Retarded • Parents' Coordinating Council and Friends	• Agnews Developmental Center • Fairview Developmental Center • Lanterman Developmental Center • Porterville Developmental Center • Sonoma Developmental Center • Canyon Springs Community Facility • Sierra Vista Community Facility • Association of Regional Center Agencies • Kern Regional Center • San Andreas Regional Center • Tri-Counties Regional Center • Westside Regional Center
State Agencies	**Other**
• California Health and Human Services Agency • Legislative Analyst's Office • California State Assembly • California State Senate (Senate Select Committee on Developmental Disabilities & Mental Health) • Senate Budgets and Fiscal Committee • Department of Finance • Department of Health Services—Licensing • Department of Social Services–Community Care Licensing	• Association of California State Supervisors (ACSS) • California Association of Psychiatric Technicians (CAPT) • California State Employees' Association (CSEA) • Union of American Physicians & Dentists (UAPD) • American Federation of State-County & Municipal Employees (AFSCME) • City of Diamond Bar • Ramey, Macomber & Associates, LLC • Other individuals

FINDINGS FROM STATES WITH STATE-OPERATED COMMUNITY-BASED RESIDENTIAL PROGRAM SERVICES

BACKGROUND

In 1967, the number of individuals residing in 165 state-operated mental retardation institutional facilities peaked at 194,650 (United States Department of Health, Education, and Welfare [1972]). Since 1968, however, the number of individuals with mental retardation served in large (16 or more persons) state-operated facilities has declined at a rate of 3 to 6 percent each year for 32 consecutive years. By June 30, 1999, the residential census in the nation's largest state institutions was down to 49,105 persons.

Institutional downsizing and closures were accompanied by a growing emphasis on supported community living for individuals with developmental disabilities. The number of community residential settings accelerated dramatically between 1960 and the present: the number of community residential settings grew from 336 in 1960 to 111,419 in 1999. The total number of individuals served in community residential settings in the United States grew from fewer than 5,000 persons in 1960 to 300,179 in 1999.

States began closing institutions in significant numbers for the first time in the early 1980s (Braddock & Heller, 1985). On January 31, 1991, New Hampshire closed Laconia Developmental Center and became the first state in the country to provide all of its services to people with mental retardation in the community (Covert, Mackintosh, & Shumway, 1994). In 1994, Vermont, Rhode Island, and the District of Columbia closed the last of their large state MR/DD facilities. New Mexico followed in 1995 and Alaska did the same in 1997. In 1999, Maine's last large facility dropped below 16 residents and West Virginia and Hawaii closed the last of their large state MR/DD facilities. Minnesota closed its last institution in the year 2000.

A notable variation on the closure/downsizing trend during the 1990s was a rapid increase in the number of small state-operated facilities. On June 30, 1999, states were directly operating 2,263 residential settings for persons with behavioral problems, needs for intensive medical supports, or who were psychiatrically involved. In 1999 alone, 69 new state-operated residential facilities were created (Prouty & Lakin, 1999). Almost nine-tenths (89.9 %) of the state-operated MR/DO facilities had 15 or fewer residents, and recent growth has been almost wholly in small settings with 6 or fewer residents.

VISITS TO OTHER STATES

In the early part of 1999, and after the recommendation of its Advisory Committee, the California Department of Developmental Services (DDS), sent several groups of representatives to five different states to observe state-operated, community-based programs. The Advisory Committee asked DDS to identify viable options and alternatives to residential and support services currently offered in the Developmental Centers (DC).

The purpose for traveling to states that are identified for their excellence in community-based, state-operated programs was to:

- Observe firsthand the successes and failures experienced in setting up those programs.
- Gather information, recommendations and advice for California stakeholders about other states' experiences in establishing these programs.
- Learn how states handled a multitude of issues, barriers, and problems that demanded practical and desirable solutions.
- Establish valuable links with the experts in other states.

At the time the visits occurred, in 1999, 18 states had some form of community-based state-operated services for persons who had been moved out of large public institutions[1]. DDS staff contacted states that had substantial numbers of such services -- New York, Minnesota, Colorado - plus the state that had most recently developed state-operated community services Oregon. Pennsylvania also was contacted because it had developed a unique and effective approach to services for persons with forensic issues. Extensive information on the services provided by these states was obtained through telephone interviews, after which visits to each state were scheduled.

DDS staff, accompanied by parents of DC consumers, regional center staff, union representatives, and others visited the five states. With the exception of Pennsylvania, all of the states have developed small community-based homes that are operated by current or former state employees. The California visitors were met with the utmost courtesy and hospitality by the hosting states, which arranged the schedule such that we could visit a range of actual residences, plus meet with state and other personnel. California union representatives met with union staff from the other states; family members met with their counterparts from the other states; DDS and regional center staff met with the state officials who had designed or who were running the services in the other state.

[1] This number grew to 20 in the year 2000.

Questions asked by the visitors from California ranged from concerns about differences in the quality of life in the community following consumers' long-term habilitation in an institution, to relative costs before, during, and after community-based state operations. Other areas of interest were funding, staff training, management, union issues, licensing, and resistance from the community. Travel to other states clearly demonstrated that effective, high-quality, state-operated programming could be accomplished in a cost-effective manner.

RATIONALE FOR STATE-OPERATED SMALL FACILITIES

Except for New York, whose state-operated programs serve more than half of New York's population of persons with developmental disabilities, most states serve only a very small percentage of their population in such settings. Of the states visited, the percentage of individuals in state-operated programs ranged between 2 and 4 percent of the total population of persons with developmental disabilities. Primarily, these programs have been set up to serve a small but visible minority of individuals who could not be served in the community services system. By the end of 1999, New York had 1,019 state-operated community facilities or 51.2 % of the national total. Nationally, 11,863 persons resided in state-operated small community facilities (15 or fewer residents) by the end of 1999. The average number of residents per state-operated community facility declined slightly between 1998 and 1999 (from 6.1 to 6.0 residents) (Prouty & Lakin, 1999).

Other states have successfully demonstrated that there is a significant and legitimate function for state-operated, community-based programs. For the population of individuals leaving the confines of the institution that need intensive medical, behavioral, and psychiatric or other highly-specialized services, states have demonstrated that the health and safety of those individuals, as well as the public's safety, can be provided through a state-operated program in a cost-effective manner. (Campbell & Hill, 1995; Greenberg, Lakin, Hill, Bruninks & Hauber, 1985; Knobbe, Carey, Rhodes & Homer, 1995; Schalock & Fredericks, 1990). Without exception, communities in each state have viewed the presence of state-operated programs as a beneficial and valuable asset.

THE FUNCTION OF COMMUNITY-BASED STATE-OPERATED PROGRAMS

Management personnel in each state reported that they saw the state as a provider of "last resort." When asked to explain, agency directors indicated that the state had to guarantee the availability of a residence if none other was available. No person's request for a residence would be rejected. States understand that the state-operated program is specially designed to provide intensive and high quality services to a small population of seriously clinically involved persons. For the most part, states provide

state-operated for persons who have:

- Needs for crisis services,
- Severe medical vulnerability,
- Severe behavior challenges,
- Psychiatric treatment needs, or who have
- Been involved with the criminal justice system.

In addition to the above programs, some states operated community based day programs, direct family support services, foster family programs, respite care, elderly/geriatric services, crisis intervention and a vaiety of conical health care services.

State-operated, community-based programs initially support only individuals who live in the institution and want to over to the community. As the state-operated program becomes more stable, individuals who live in the community and are at risk for being placed in an institution are given the option of receiving services through the state-operated program. The scope of services offered by state-operated programs varies with the length of time in operation and the number of persons served by the state.

In several of the states visited, advanced training services were offered by the state to enhance skill levels among private sector care providers and health professionals with limited experience providing services to the developmentally disabled. A consistent guiding principle among all of the states visited was to preserve and extend into the community the expertise among DC staff via its state-operated program. States expertise held by DC staff continued to benefit individuals with developmental disabilities well into the future.

THE "CENTERS OF EXCELLENCE" APPROACH

The general definition of a Center of Excellence is: "a training center that is a part of the continuum of care for person with mental retardation and serves as an integral resource for the community by providing needed medical, behavioral, and dental services, sharing facility staff expertise in new service approaches, and training community staff." For the most part, this means that the DC finds ways to share the expertise of its staff with person living in the community.

Minnesota offers a good example of this service modality. The state-operated Minnesota Extended Treatment Options (METO) program provides extensive outreach and support services so that individuals can be served in the least restrictive setting necessary. With outreach and support services available, admission to the specialized residential program can be limited to those few individuals who exhibit such extreme behaviors that they cannot be served safely in their communities. In some cases, the METO individualized assessment leads to the identification of necessary supports and services that can be readily put into place so the individual can rapidly return to his or

her regular community setting. In other cases, the individual will not be able to return safely to the community until substantial treatment is completed and/or until substantial planning and modification of community services and supports has occurred.

In New York, DC staff that formerly provided services directly to individuals living in the institution were made available to consult with families, care providers, and vendors in the community for the sole purpose of keeping the community placement for the individual safe and healthy. State staff consulted directly with schools and supervised crisis interventions to keep individuals' school or residential placements secure. Friday to Sunday evening respite was provided on the DC grounds. Technical assistance was available to community providers who needed short-term training to improve the quality of their services. Staff intervention was always preventive in nature.

Two smaller states, Virginia and Kentucky, also offer examples of the centers of excellence concept. These states are geographically smaller and have a smaller population of persons with developmental disabilities than those we have discussed. The most severely involved individuals remain on the DC grounds while others move to nearby neighborhoods or counties. Professional staffs with high levels of expertise visit local communities to support the needs of persons who live in the community and to train local professionals. For example, the Northern Virginia Training Center (NVTC) serves 200 persons who reside on the grounds of the DC but it also serves many hundreds of individuals with intense medical and behavioral needs who live in the 5 counties around Washington, DC. NVTC recognized that if it was going to have a future, it had to establish an essential role in the community. Because NVTC received frequent requests from previous NVTC clients for clinical services, it recognized there were lots of unmet needs in the community.

The NVTC has established a broad-based system of services, of which 90 percent are provided in the community and 10 percent on the grounds of the DC:

- Through relationships it developed with 20 Universities, NVTC provides internships, externships, and/or practicums in OT, PT, nursing, therapeutic recreation, psychology, social work, speech and audiology, and it offered to provide Universities with psychiatry and neurology rotations.
- Consultations services are provided in the areas of dermatology, orthopedics, podiatry, cardiology, ENT, ophthalmology, urology, gynecology, genetics, psychiatry, gastro-intestinal, neurology, dental, and anesthesiology for dental services.
- Extensive training of residential service providers, families of persons with developmental disabilities, and county staffs is provided.
- Psychological and behavioral assessments of individuals with challenging behaviors are provided.
- Staff from NVTC conducts house calls and they set up referrals to outside community medical specialists and other clinical disciplines not offered on the NVTC grounds.

REPORTED TRENDS AND FINDINGS

Visits to states with the very best state-operated community-based programs, produced valuable information. Delivering services in a community setting creates opportunities for innovation that may not exist in the institution, and at the same time, forces discovery of cost saving and cost-management techniques.

Emphasis on Individualized Assessment

Every state visited emphasized the importance of a carefully conducted person-centered assessment before the consumer is moved from the institution to the community. Persons living in institutions, who depend on support 24 hours a day, require extremely careful planning and coordination to ensure that those same services or better services are available in the community. Individuals cannot be moved from the institution on the assumption that community medical, dental, and other essential services will be there. The fragile medical nature, or unstable emotional nature, of this population requires highly-individualized assessment for treatment intervention and identification of a safe and appropriate residential setting. For example, individuals who are nonambulatory, nonverbal, and require periodic medical intervention will need a living space that addresses the consumers' and staffs' rights to a healthy and safe living/working environment. Individual profiles on each consumer are required to identify the optimal neighborhood, housemate and necessary community resources.

Years of experience in safely moving individuals to the community underscored the importance of developing a comprehensive, realistic individualized plan before the move. A person-centered plan begins with documented service needs; incorporates input from family, friends, DC and regional center staff; and ends with the creation of the resources needed to make the plan work. The plan will determine core responsibilities of support, which then determines the specific activities that lead to resource coordination and development. The level of detail reported by states that have already developed sophisticated individualized assessment procedures, demands a well-coordinated, highly-organized effort on the part of all caregivers.

Consumer and Family Effects

In each of the states visited by DDS and stakeholder representatives, the conclusion regarding the impact on the lives of persons moving to the community was the same. Regardless of their level of functional ability or intensity of need for services, individuals:

- "Brightened" within 1 to 3 months after moving from the institution into the community.
- Received increased amounts of personal attention and one-on-one contact, including physical touching.
- Improved in awareness, motivation, and the need and attempts to communicate.
-

Studies that investigate the quality of life of persons moving from a large institution into the community, report similar results; e.g., Emerson and Hatton, 1996; Larson and Lakin, 1989. The effect on the individual's family was also positive. Family members, on average, were more likely to visit their son or daughter after they moved into a state-operated home in the community than they were to visit the individual when they lived at the DC.

In several states, DC parent groups that initially opposed reducing the size of the institutional population and were afraid of moving their relatives to state-operated programs in the community, eventually reversed their belief that healthy and safe environments could not be constructed in the community. Oregon is a case in point. The majority of parents who vehemently opposed closure of Fairview in Salem, Oregon now, just as adamantly, support the state-operated program. They have formed themselves into a "quality assurance monitoring" group that reviews the homes to which persons moved when they left the DC, and they are very pleased with what they have found in these visits.

Size of Residences

A consistent trend in every state visited was the reduction in the size of state-operated, community-based facilities. Over a period of 15 years, the number of persons in a residence reduced, on average, from 15 or more down to 4 or less by the late '90s. In New York, California visitors were taken to a community-based medical home that housed 12 residents, which was opened 15 years ago. Then they were taken to a newly-established 4-person home. New York's current policy is to develop residences for four or fewer persons whenever feasible. The Pueblo Consortium in Pueblo, Colorado provides medical supervision and care in residences for three individuals. Oregon found that a 5-person medical facility was an appropriate number of residents in a single home for persons who are medically-fragile. For individuals with less intense medical needs; i.e., diabetes and seizure disorders, Oregon places three individuals into a single residence. This is not to imply that a smaller residence is always necessarily the best living arrangement, just that these states found the smaller residence to be safer, easier to manage, and more conducive to positive outcomes for consumers. There may be circumstances where six or more individuals living together could constitute a mutual benefit.

Medical Services

In states where state-operated programs were newly developed, DC staff went into the community and established the required medical and nursing services, created health insurance liaisons with HMOs, and initiated other essential preparatory efforts to identify and secure resources. For example, in Oregon, the state worked with HMO officials to recruit, screen, and train physicians who could be assigned as a primary care physician before the individual moved to the community.

In the five states visited, state-operated programs developed community networks, using local medical resources, to address the medical needs of individuals who moved from the institution. Developmental Center medical staff was involved in the most complex cases and traveled from a geographically-central location into the community to consult and/or provide medically-coordinated advice. To establish the appropriate medical services in the community, local HMOs were contacted and asked to coordinate the provision of specialized services for persons with developmental disabilities. Most HMOs have an "Exceptional Needs Health Services Coordinator" position to accommodate the development of unusually complex medical services.

Each state clearly demonstrated that it is possible to create support networks that result in highly integrated living environments. States reported that they were surprised to find out, contrary to conventional beliefs, that the safety and health of the medically involved individual was significantly easier to maintain than anticipated. Relocating medically-fragile individuals turned out to be the relatively easiest population to manage.

Behavioral Services

Managing individuals with challenging behavior, including serious aggression, self-injury or property destruction, was the most difficult problem faced by former DC staff assigned to create behavioral programs in a community-based residence. DC staff is prepared to manage serious behavior problems by their extensive training and experience. The community environment offers an advantage over the DC environment in controlling negative behaviors; i.e., in the community there were significantly more natural and intrinsically reinforcing events to be used to motivate positive behavior. State-operated programs were uniformly successful in providing treatment for behaviorally-challenging individuals by developing highly structured treatment environments. Community-based treatment programs use a technique that incorporates awareness of self-responsibility. Treatment intervention activities are designed to promote ways for individuals to achieve greater self-control by reinforcing their positive behavior with greater access to community activities. Treatment activities were continuously focused on returning the individual to a lesser restrictive environment by reinforcing responsible behavior on a moment-to-moment basis. Staff ratios in state-operated residences were roughly the same as on the units of the DC, but reduction in negative behaviors tended to be faster in community facilities.

Housing

Some states, such as New York, opted to purchase land and build and own a relatively large inventory of homes. Other states, such as Colorado, opted to build new homes by taking advantage of federal housing programs and creating incentives for nonprofit housing development corporations. Across all states visited, homes were built and owned by the state, or built by non-profits and leased back to the state. Some states purchased and remodeled homes for suitable use for specific populations or leased

from private owners.

Except in rare instances; i.e., where a residence is needed for only a relatively short time, leasing is the least-preferred option. Leasing permits greater flexibility for change but is more expensive. New York, a state that owns a large inventory of small homes, manages its housing assets to optimize savings for the state. New York has acquired a knowledge base for determining where and how many homes a given community can absorb before political opposition increases.

In contrast to New York, Oregon chose not to own homes but instead created incentives for housing development corporations to build and manage homes specifically designed to meet the special needs of selected populations; i.e., behavioral, psychiatric, and medical needs populations. Oregon purchases the land and designs the building plan for the specific need served. Site location is determined in part by the needs of the residents selected to move to a specific home. Persons with medical needs are more likely to be located closer to health facilities and persons with challenging behavior are more likely to be located on larger acreage and in more remote areas away from schools and business districts. Walking distances to stores, parks, recreational areas and access to public transportation are also considered. The first priority used by states in determining a residence location for individuals, is whether or not the individuals are able to reconnect with their families. Specific regions, cities, or towns are identified that meet the individual's and family's need.

In Oregon, the assets contained in the land where the former DC was located were transferred, per authority of the Legislature, for use in the development of community-based, state-operated residences. The key to Oregon's success was in retaining assets and revenue allocations for state-operated community programs that were assigned to DC operations.

In rural communities, local citizens see state-operated homes as an economic opportunity. In urban areas, the approach may be perceived as a drain on property values and appreciation as well as a loss in tax-base, because the home is federally-funded and not providing tax payments from income earned.

Design And Development Of Specialized Housing

States that designed and built homes eventually determined what constituted a "tried and true" design model. Data from states with the most successful design strategies has been evaluated and residential designs appropriate to selected sub-populations of persons with developmental disabilities are well known. The design of each type of residence is specific to the type of program that will occur in the home. Specially designed residential homes are almost always built for persons who exhibit aggressive or destructive behavior and have enduring medical needs,psychiatric disorders, or mobility problems. Housing specially designed for persons with behavioral and intensive medical needs are necessary to maintain the health and safety of residents as well as

the staff who care for them. A living space suitable for persons with developmental disabilities is designed to meet the needs of the persons who will be living there. For example, design features must include consideration for:

sound-proofing
wall-hardening
built-in medical equipment
security features
fire and safety code requirements
special equipment installations
arjo tubs
floors
built-in lifts
transport devices
space requirements for transport and transfer of clients
selection of equipment that is resistant to damage
type of doorways used
hardening of interior walls
unobstructed line-of-sight through interior halls
mobility ramps

Other design considerations include strategically-located parking spaces; safety features that eliminate or reduce risk of injury to staff; ample storage space; access to and convenience of cleaning surfaces and equipment.

Management Issues

Management of state-operated, community-based residences present special problems because there are numerous small homes distributed throughout a relatively wide geographic region. Both New York and Oregon accomplished adequate management strategies by designating regional managers who were directly responsible for supervising a fixed number of homes. Each home has its own House Manager. The House Manager supervises the direct care staff and is responsible for coordinating the special consultants assigned to the home. The goal is to cluster homes as densely as possible to maximize support costs such as transportation, work programs, and day activity programs without negatively impacting the community. The objective is to establish the day program as the hub with routes to nearby homes as the spokes to the hub to hold down transportation costs. The state clusters homes for optimal manageability; a 20-mile radius is typical for a cluster of state-operated homes.

Day-to-day operations are the responsibility of a House Manager and a shift supervisor. Typical responsibilities include staff scheduling; developing and managing a budget for the home; ensuring compliance with licensing regulations;and family, case management, and support agency contacts. Specialists on each shift implement program plans and other specialists; e.g., vocational, habilitation, and recreational specialists develop and maintain employment or alternatives to employment, training in daily living skills, and structured recreational activities. Consultant contracts for some services are competitively bid because there is a cost saving over maintaining a full time equivalent position.

Direct care staff performs the day-to-day chores including cooking, cleaning, grocery

shopping and laundry. Care staff is trained to involve consumers as much as possible as to create teaching opportunities for community living. Direct care staff is not expected to perform routine repairs on the house. Typically the state keeps a maintenance and repair fund for repairs over a specified amount, or, in the case of non-state ownership, the non-profit housing owner is responsible for maintenance repairs.

Quality Assurance And Training

Each of the states visited was authorized to conduct their own quality assurance operations. The emphasis was on developing "point of service" awareness of the need for quality care. Direct care providers were trained to a competency criterion and expected to maintain a minimal standard of care as a condition of employment since each state was authorized to conduct its own quality assurance program, states supervised their own state-operated programs in the community, and the maintenance of a quality assurance standard was integrated into daily operations.

The change in the work environment, as DC staff migrated from the institution to the community, required special training to assist DC staff in coping with new demands and responsibilities. The role of a DC employee changes from being almost exclusively a direct care provider to being a direct care provider and an ambassador of community-relations. Staff was given community orientation training that included awareness of community resources, communication procedures, transportation options, program standards, etc. Core competency training for direct care staff was implemented before the transition to the community. Staff was closely supervised during the first few months after the move to the community. Staff received hands-on training for implementing positive behavioral supports and training for conducting continuous individualized assessment necessary to keep service programs current.

States reported that more staff team building and personal commitment was required in the small community residence than had been necessary in the DC. Because the personnel in each home constitutes a small team that functions relatively independently of the larger management team, more individual judgment and on-the-spot decision-making must occur to ensure that the program functions smoothly. Compared to a privately-operated home, turnover among staff in the state-operated facilities was significantly lower.

Union Issues

As states initiated community-based, state-operated programs, collective bargaining with unions was central to a successful beginning. Typically, states made every effort to preserve every union job. The common strategy used to preserve the expertise of union employees was to offer each employee the option to move to the community along with the consumer or retrain for an equivalent position in another institution. Special incentives were offered in some circumstances; e.g., opportunities for risk pay

adjustments for secure workers. Unions in each state described positive relationships with management. In some cases, weekly meetings between the union representative and management were held to resolve disputes as soon as they occurred. Union staff was given the option to bid for a desired change in job location based on their seniority.

In Oregon, DC plant support and maintenance staffs were offered the opportunity to upgrade to direct care staff positions. Training during this "transition program" was provided by the state. In all the states layoffs were avoided almost entirely. The goal was to maintain job opportunities, which was a strong selling point for unions. The union was an essential partner in making state-operated programs happen. Unions were involved in the process from the beginning. As a consequence, morale was kept high as new services in the community were developed. Initially, there was resistance to change by some union employees, but within 6 to 12 months the resistance was replaced by a strong endorsement for establishing community-based programs.

LEGISLATION

States obtained legislation to enable transfer of assets allocated to their DCs to the state-operated programs in the community. Most of the states visited sought legislation that permitted the operation of secure facilities. Most states visited required legislation that permitted streamlining the licensing and certification process. Several states needed supporting legislation to address the disparity between private and state employee rates of compensation. The process of educating the Legislature about the advantages of state-operated community programs helped to clarify the direction of public policy. A public policy initiative was the first, and essential, step to unifying the separate political factions within the state.

COSTS

States reported two findings regarding the overall costs of establishing a state-operated, community-based program as an alternative to continuing operation of the institution:

- Initial costs are significantly higher because it is necessary to run a dual operation until community resources are sufficiently established to absorb all institutional residents. This period of time ranged between 5 and 10 years for the states visited.
- Over the long run, costs per individual become lower than institutional costs because savings can be realized by more flexible contracting for services, less capital outlay for infrastructure, and operational costs can be trimmed more efficiently.

Several published studies, that examined the relative cost of institutions and community services, have found that expenditures for recipients of community services were reduced from 75 % to 95 % of the costs for large institutions (Campbell & Heal, 1995; Greenberg, Lakin, Hill, Bruninks & Hauber, 1985; Knobb, Carey, Rhodes & Homer,

1995; Schalock & Fredericks, 1990). Comparison of the relative costs between the institution and community settings depends on factors such as certification status of the home, funding program, age of the facility, residence size which affects staffing ratio, and public or private ownership. Higher staff wages in state-operated facilities tended to drive costs higher relative to the institution. A recent study Stancliff & Lakin, 1998, found that per-person costs in Minnesota were 32.5 % higher in state-operated settings compared to the private group homes, but were lower than the cost for the same services in the institution. Therefore, the cost of state-operated community residences falls between the costs for private community residences and the large institution.

CONCLUSIONS

The standard of service for persons with developmental disabilities today strongly emphasizes individualized services in small settings with access to mainstream lifestyle activities in the community. The Lanterman Act mandates that individuals with developmental disabilities receive individualized services that meet their particular needs and preferences, and that they live in the least restrictive environment and close to their families' homes. A desirable alternative to long-term care in institutions is a smaller, community-based model of service. California is in an optimal position to implement state-operated, community-based delivery of services as an option for persons who reside in large institutions.

Taken as a whole, the stakeholder representatives who traveled to states with successful state-operated programs came back with a favorable impression of the state-operated option. Other states have visibly demonstrated that there is a role for former DC staff in the delivery of healthy and safe services necessary to individuals as they move from the institution. In the states visited, well-managed state-operated programs with highly-specialized services were delivered in a cost-effective manner. For a small but select population of individuals who are medically, behaviorally or criminally-involved, the community-based state-operated approach is a logical alternative, especially for states that have insufficient numbers of privately-operated programs. Community-based, state-operated programs have been successful at providing highly-specialized services for a small population of persons (approximately 2 to 4 percent of a state's total number of developmentally disabled residents). (See Knobb, et al., 1995, for supporting evidence of this conclusion.) For individuals with complex service needs, the community-based, state-operated program has an important role in helping states meet the higher federal standards that require individualized living options, a home that is safe and flexible, and offers individual choice, independence, productivity, community integration, and increased consumer satisfaction.

The following points reflect the central elements of the process that leads to the beginning of a state-operated service delivery agenda:

- Learning to care for persons with developmental disabilities requires training and experience. A large portion of DC staff has high levels of valuable expertise. Transitioning seasoned DC employees into community-based programs preserves the competency and know-how required by those who care for individuals with the most intensive needs. The skills and expertise are not only preserved and improved upon for future generations, but are also shared with private providers and professionals in the community.
- The length of time to establish a state-operated program to serve developmental center clients who decide to move into the community can take 5 years. Depending on how deeply the scope of the operation is defined, it can take up to 15 years.
- Individualized assessment and resource coordination and/or creation were essential to the safety and health of individuals who moved from the institutional setting into the community.
- Smaller is better. The message from every state visited was that the smaller the residence, the safer and healthier the environment. Smaller residences are as easy to manage as the large institution.
- One message from administrators and managers in other states was that agreement among stakeholders and the state is absolutely essential to achieve an acceptable outcome. Agreement among stakeholders drives the planning process. Stakeholder agreement leads to valuable support necessary for accomplishing legislative change. Each state involved their local constituencies in the planning process.

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Attachment 3

Developmental Center Options Study

Final Report

Prepared by

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For

Department of Developmental Services

February 2001

Note: this report was prepared by an independent consultant. The principals and assumptions contained herein do not necessarily reflect the views of the Department of Developmental Services.

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Developmental Center Options Study

Executive Summary

Overview

The Department of Developmental Services (DDS) provides direct services to more than 3800 individuals with developmental disabilities in five developmental centers and two leased facilities. The buildings and infrastructure of the five developmental centers are old and in need of repair. In 1996, DDS contracted with Vanir Construction Management to conduct a study of the infrastructure of the five existing developmental center campuses. Vanir estimated that it would cost between $800 million and $1.5 billion to repair or replace the existing structures to bring them into compliance with current building codes and/or programmatic requirements.

The report generated considerable interest in the State. In 1998, DDS initiated a planning process to explore and develop options for restructuring the developmental centers. The process included establishing an Advisory Committee to help determine the future of state operated services; visits to other states that have developed small community based homes to serve people who had resided in developmental centers; and adoption of five principles guide the study of options for developmental centers.

1. No capital outlays to rebuild developmental centers.
2. Homes limited to four persons or less.
3. Capture and extend developmental center resources into the community.
4. Leverage the developmental center land to create new resources.
5. Conduct highly individualized personal assessments and resource development before the move to the community.

A Trailer Bill was enacted as a part of the adoption of the 2000-2001 budget that requires DDS to report to the Legislature by March 1, 2001 on a range of options to meet the future needs of individuals currently served, or who will need services similar to those provided, in state developmental centers. In September 2000, a study was undertaken to gather information from stakeholders to use as a basis to prepare the report to the Legislature. The scope of the study included conducting focus groups and interviews with families of developmental center residents, consumers who reside in the developmental centers, consumers who reside in the community, and a wide variety of people at the local and state levels on their opinions about the range of options. The information was organized into a draft report that was presented to the Advisory Committee in November 2000. The final report was prepared based upon suggestions made by the Advisory Committee.

Data Collection

Information was gathered from all of the major groups associated with the developmental disabilities service delivery system. Over 850 people actively participated in the discussions that are summarized in the 90 appendices to the report. The information was gathered in 26 focus groups, five meetings of developmental center parents, 49 face to face or telephone interviews, and 10 written submissions. Numerous letters and emails were received during the course of the data collection. These were incorporated into the final report as well.

Summary of Findings

Values

Participants felt that stability is an important value in services and supports and that stability is a key component of quality. People generally agree that quality begins at the direct care staff level. People value staff that is qualified, trained, stable (low turnover), fairly compensated and compassionate. Families and consumers want services they can rely on and that are open, accessible, safe, welcoming, and well monitored. Services should have standards, be vested in quality, have clear lines of accountability, and have ongoing staff training and supervision. Consumers want a full life that includes freedom, activities, work, friendships and other relationships.

People want the principles and values of the Lanterman Act to be the principles and values of the whole community system, regardless of who is responsible for delivering the services. If the state is going to operate services in the community those services must be a part of the community and not separate “mini institutions”. There was consensus that DDS is the safety net for the system and will continue to play that role for some groups of consumers.

Principles

<u>No major capital outlays to rebuild developmental centers</u>

Community members tended to agree with this principle. Developmental center parents groups and others raised questions about how this principle was reached. There were many questions about the basis of the Vanir estimate for rebuilding developmental centers and conjecture that the cost of developing four person homes in the community for 3800 people may exceed the cost of rebuilding developmental centers.

<u>Homes limited to four persons or less</u>

This is the most controversial principle. Some, who fully support the principle, cautioned that it should not act as a limitation to consider other options such as supported living nor should it result in mini institutions in the community. People pointed out the conflict between the language in the Trailer Bill that calls for consideration of all options and the presentation of a principle that places a numeric limitation on the size of

any option. Others questioned the economic viability of the option, particularly for ICF/MR facilities. Suspicions were raised that the adoption of a four-person home was an attempt to circumvent licensing requirements.

Capture and extend developmental center resources in the community

The concept of extending developmental center resources in the community received considerable support. It is generally acknowledged that developmental centers have expertise that is difficult to access in the community. There is also consensus that access to the services would strengthen the community. There are suggestions related to the use of innovative methods to extend the services. However, there is not consensus on who should be responsible for managing the resources. Regional centers would like to see the resources become a part of the community service system. There is also concern about limiting the recipients to current developmental center residents.

Leverage the developmental center land to create new resources

Discussion on leveraging developmental center land fell into two general categories. Some people support this principle with the caveat that the gains realized from the land be dedicated to the developmental disabilities system. There was not a lot of support among the developmental center parents groups for leveraging the land. They prefer to keep and use the land.

Conduct highly individualized personal assessments and resource development before the move to the community

This is the most universally accepted principle. The comments tend to fall into four categories. There are suggestions that this should be the first principle since it drives the development of options. There are comments that this is the law and should be going on now. There is a concern raised that the highly individualized personal assessments and resource development should not be limited to residents of developmental centers but should available to consumers in the community. The final category includes many suggestions on how to improve individualized planning.

Planning Structure

There was consensus has that all stakeholders should be involved in the planning process. While people were not specifically asked to comment on structure, there were several good suggestions for planning structures.

- A bottom to top structure that suggests that principles to guide the planning be developed and implemented starting with a comprehensive planning and assessment of persons who reside in developmental centers. Service design and development will be based on individualized assessments and completed on a regional basis. The role of the state is to support the regional efforts.

- A regionalized structure with decentralized planning on a regional center or multi-regional center basis. Regional centers would develop plans individually that would

be integrated into the range of resource needs within their local communities. The coordinated proposal would be submitted to DDS. The regional centers would negotiate with the state for funding, resources and the ultimate objectives of the plan. The role of the state would differ from plan to plan.

- A local planning area structure where the state assumes a leadership role in defining criteria for the plan with regional planning groups empowered to actually implement portions of their local plans. The planning groups could be based on what stakeholders and others felt were compatible planning areas. The master plan could be developed through contract. The plans would address local needs and resources.

- A pragmatic approach that involves all of the stakeholders. The process is structured to make it manageable. In this approach DDS defines and sets the objective of the plan. A small representative group would do the actual planning. The role of the planning group is to help with the tactical questions and issues associated with implementing the objective.

- Multi-tasking instead of linear planning and implementation. It begins with a decision that planning and implementation can move forward simultaneously. Within the stated objective of the planning process there are a number of things that have been clearly defined as needing to be done regardless of what final decisions are made in the plan. The clearly defined areas can be addressed and efforts made to ahead on them while the larger planning effort is underway.

<u>Major Themes/Issues</u>

- People want a unified system in the community. There is great concern that state operated services in the community will result in a two-tiered system where there is not equity in access to resources and where consumers with similar needs get a different kind and level of service based solely on their current residence. Concern was expressed that a two-tier system would only serve to destabilize the community system. There was discussion on what the system role of DDS should be. Of particular interest was whether the role should be limited or expanded to areas that would strengthen the entire community system, i.e., training, expanding scarce resources such as specialized equipment engineering and maintenance, etc.

- A second theme is concern about relationships between the community operated and the state operated services. People want to know how the system will operate. Will there be the same standards? Will state operated services operate under the same licensure and regulations as community operated services? Who will monitor the services? Who will be responsible for placement, service coordination, and quality assurance? How will consumers move in and out of state operated services?

- A third theme is related to defining the groups that the state will serve. There is consensus that the state should serve the forensic population, but the population needs to be better defined. If other groups are to be served, people thought that

they need to be identified. Another issue is who will make the decision as to whether the consumer meets the criteria for state operated services.

- The fourth theme is quality assurance for services and supports. Quality assurance was identified as a need in the system. People feel that the current quality assurance efforts are not sufficient to assure quality. People felt that the same quality assurance system should apply to both state and private services. The identified components of a quality assurance system include licensure, regulation, standards, best practice, training, and monitoring, including unannounced visits. There was some concern expressed that the emphasis on licensure may serve to impede development and availability of non-licensed setting such as supported living.

- The fifth theme concerns how state employees and resources will be transitioned into the community. There is consensus that moving direct care staff from developmental center settings to the community will require training and a period of transition. Moving developmental center resources into the community is considered to be a good idea. People were enthused about having access to resources that are hard to find in the community, but there was recognition that it will be difficult to make the services available throughout the state. The discussion about how to move scarce resources into the community included some excellent suggestions. For example, traveling assessment teams, telemedicine, and apprenticeship programs were suggested. Placement of responsibility for managing the resources was also discussed. Some suggest that they be attached to regional center.

Options

Gathering opinions and suggestions about options was a major focus of the project. People were provided with a preliminary list of options for comment (Attachment C). They were also encouraged to make suggestions for additional service options.

<u>Residential</u>

- There was general support for a state owned option. Ownership of the home would satisfy the need for long term stability of living arrangement. It was viewed by some as being more important than the actual operation of the home by the state.

Participant comments about options on the list

- *State staffed homes in the community for four or fewer people where the home is leased.* There was concern about the stability of a lease. There was a suggestion to have the foundations connected to regional centers be the nonprofit agency who owns the land.

- *State provides special supports to privately owned and operated homes*. The concern about the stability was raised in this option as well. There were also some who felt the state would be better served by augmenting rates to community providers to allow them to serve the consumers without state involvement.

- *Person lives with family; state provides services.* The families of developmental center residents did not feel that this was a viable option for them because of their age and the age of their family member. They did think that it might be a good option for families who needed help to keep their family member from going into the developmental center. People in the community questioned why the state couldn't just provide more funding for the services.

- *Supported living* received support and some very specific suggestions about how to make it work. One suggestion was to help state employees start supported living agencies. There were several suggestions about the need to be able to augment the rent for consumers and to remove the cap on expenditures. The LA Autism Society reported that supported living arrangements had proven to be the best option for their family members. People First of California listed this as the preferred option.
- *Host adult family homes for one or two consumers received support*, but it was pointed out that there had not been wide spread development of this option in the community. Part of the problem is the restrictions on current state employees being able to operate the homes.

- *Self-determination* received support. One comment was made that the state would have to deal with the issues related to developing resources to meet some of the needs.

Day activities

Participants comments about options on the list

- *Options to use existing day activity program was considered a viable option if there was the ability to augment staff resources*. There was concern expressed about the option to send a residential staff person along. Suggestions included removing barriers to participation by people with health issues in existing day program.
- *State provides day program* did not receive a lot of comments.
- *Options where residences would provide the day program* were not considered good ideas. It was felt that the consumers needed more variety in their lives.
- *Option where one residence develops the day activity program* was not considered to be a viable option. In addition to the concern expressed above, there were concerns expressed about the loss of an extra set of eyes to monitor for abuse and neglect. It was suggested that if the person could not leave the residence for a day activity that an outside agency be brought in to conduct the program.

Other services

Participants comments about other options

- *Regional resource centers* were considered to be a good idea but there was strong support for the resources to be used to strengthen the community and not be a

separate system from the community. It was suggested that the resource centers be attached to regional centers. It was also suggested that the state be the provider of last resort.

- *Crisis homes, intervention teams and respite beds* were considered to be good ideas but there were suggestions that the homes and respite beds be available to children and adults.

Participants comments about an option to build on developmental center land

The families of developmental center residents and the City of Diamond Bar were in favor of this option. Community people were generally opposed to this idea.

Developmental Center Options Study

Overview

The Department of Developmental Services (DDS) provides direct services to more than 3800 individuals with developmental disabilities in five developmental centers and two leased facilities. The buildings and infrastructure of the five developmental centers are old and in need of repair. In 1996, DDS contracted with Vanir Construction Management to conduct a study of the infrastructure of the five existing developmental center campuses. Vanir estimated that it would cost between $800 million and $1.5 billion to repair or replace the existing structures to bring them into compliance with current building codes and/or programmatic requirements.

The report generated considerable interest in the State. In 1998, DDS initiated a planning process to explore and develop options for restructuring the developmental centers.

Major Activities of the Planning Process

The planning process began in November 1998 with the release of the Vanir report. The major activities are listed below.

- Creation of an Advisory Committee to help determine what the future of state operated services should be. The membership of the Advisory committee is representative of the major stakeholder groups in the developmental disabilities service delivery system. The Committee met in December 1998, June 2000 and November 2000.

- DDS staff, accompanied by parents of developmental center consumers, regional center staff, union representatives and others visited five states: New York, Pennsylvania, Minnesota, Colorado and Oregon. With the exception of Pennsylvania, all of the states have developed small community-based homes that are operated by current or former state employees.

- The second meeting of the Advisory Committee was held in June 2000. Information from the visits to other states was discussed. Presentations were also made by persons who had been involved in developing the homes in the states of Oregon and New York.

- Five principles were presented to and accepted by the Advisory Committee to guide the study of options for developmental centers.
    1. No capital outlays to rebuild developmental centers
    2. Homes limited to four persons or less
    3. Capture and extend developmental center resources into the community
    4. Leverage the developmental center land to create new resources

5. Conduct highly individualized personal assessments and resource development before the move to the community

A Trailer Bill was enacted as a part of the adoption of the current year budget that requires DDS to report to the Legislature by March 1, 2001. Specifically, the Trailer Bill language states:

a. *The State Department of Developmental Services shall identify a range of options to meet the future needs of individuals currently served, or who will need services similar to those provided, in state developmental centers.*

b. *The department shall establish a workgroup consisting of system stakeholders to assist in examining the various options including, but not limited to, renovation of the existing developmental centers, smaller state owned and operated facilities, and services and supports provided in consumer owned or leased homes.*

c. *Options shall be evaluated for their appropriateness in meeting consumers' needs, compliance with requirements of federal and state laws, and efficient use of state and federal funds.*

d. *The department shall report on these options and the recommendations of the workgroup to the Legislature by March 1, 2001.*

In September, a study was undertaken to gather information from stakeholders to use as a basis to prepare the report to the Legislature.

Scope of the Developmental Center Options Study

The study has four major tasks.

- Conduct focus group sessions on the options in at least five regions of the state with families of the developmental center residents, consumers who reside in the developmental centers, consumers who reside in the community and others.
- Interview a wide variety of people at both the local and state levels on their opinions about options.
- Organize the information and prepare a draft report answering the Legislature's questions. The report will be presented to the Advisory Committee in November.
- Revise the report based upon the input from the Advisory Committee.

Methodology

<u>Information packet</u>

At the outset of the project, an Information Packet was assembled by DDS that included an overview of the issue and planning process, the Trailer Bill language, a statement of the five principles, information on the Advisory committee, an excerpt from the Vanir report and information on how to submit comments. The packet was given to all of the individuals who were interviewed, to people participating in parents meetings, and to most of the focus group participants. Information packets were also given to various

organizations for distribution to their Boards or other interested parties. The information packet was posted on the DDS website as well.

Discussion questions

Common questions were developed and used for the interviews, focus groups and developmental center parent group meetings. The original list of questions was "field tested" at Agnews Developmental Center in early September. The flow of the questions did not lend itself to gathering all of the information. The questionnaire was amended with the help of the parents, consumers, the regional center and developmental center and concurrence of DDS. Two versions of the amended questionnaire were used, one for the community at large and the other for the developmental center parent groups meetings. Attachment A contains the amended community and developmental center parent group meetings questionnaires.

Questions were developed for focus groups with consumers. The questions are also included in Attachment A.

Specialized interviews were conducted with the Department of Health Services, the Department of Social Services Community Care Licensing, six parents whose family members had moved from a developmental center, and one consumer who had moved from Camarillo. Each of the interviews was designed to elicit specific information.

The DHS and DSS interviews were held to find out what, if any barriers or issues may arise in restructuring developmental centers.

Parents whose family members had made a successful move into the community were asked what had made the transition a smooth one, what didn't work and what could have been done to make the transition more positive.

The consumer was asked for similar information as the parents, but from his/her perspective.

Focus groups, parent groups and interviews

Over 850 people actively participated in the discussions that are summarized in the 90 appendices to this report.

Focus groups

For the purposes of this study a focus group is defined as any group where the information was taken using a facilitator who took notes on a large flip chart. Participants were cautioned to make sure that the information being recorded reflected their views. The information gathered during the focus groups was summarized in a uniform format developed for this report. Each focus group is presented as an appendix to the report.

Twenty-one focus groups were held during September and October. In addition, the People's First Group at Sonoma Developmental Center conducted their regular meetings as focus groups to consider the questions developed for consumers.

Developmental center parent groups

The parent groups at the developmental centers hosted five meetings. The meetings were very well attended, ranging from 50 to 135 family members. The meetings began with an overview of the project by a DDS staff member followed by a focus group. At Agnews Developmental Center, the families broke into small groups facilitated by developmental center staff that recorded the information on large flip charts. The parents chose to stay in the larger group at Sonoma, Fairview, Porterville and Lanterman Developmental Centers. Several staff people from each of the developmental centers recorded comments on flip charts. The Sonoma meeting was video recorded.

Letters and emails were received from developmental center family members. Some of the emails and letters were from family members who were unable to attend the meetings and wanted to provide information. Other letters came from family members who attended and wanted to add comments. The information provided in the letters and emails was incorporated into the five appendices for the parent group meetings.

Interviews

Forty-eight interviews were conducted. For purposes of this report, an interview is defined as a face-to face or telephone meeting with one or more people where the interviewer takes notes. Generally, the information gathered during the interview was summarized in the format and returned to the person(s) who participated. The interviewees were asked to edit the information so that it was an accurate reflection of their position. The content of interviews with the six parents and one consumer were verified with the person at the end of the interview.

Written responses

Written responses received from seven people or organizations are presented as appendices. The responses are presented as they were received. There is also an appendix of notes taken at the CASH/PCR Board meeting in September.

Other information

Other information was provided during the course of the data collection. This information includes adopted positions, letters and emails. Where the letters or emails were from people or organizations that had been interviewed, the information in the letter was compared to the summary to determine whether new information had been provided. Adopted positions were included at the request of the person or groups that were interviewed. All of the information was given to DDS.

Information from developmental center employees

The scope of this study did not include developmental center employees. Information received from employees was given to DDS to include in its information gathering efforts with that group.

Revisions Based Upon the November, 2000 Meeting of the Advisory Committee

The draft report was presented to a meeting of the Advisory Committee in November 2000. The committee made a number of suggestions for revisions to the draft report.

- Expand the scope of the report by including information from consumers who reside in the community, family members of consumers who reside in the community and others who had not been interviewed for the draft report.
- Clarify and define "community" and "safety net".
- Prepare an executive summary to the report.

The report has been revised in accordance with the suggestions. Information was gathered from focus groups with the LA Autism Society and People First of California. Written statements were received from the Mayor Pro-Tem of Diamond Bar, the Chairperson of the Sonoma Developmental Center Governor's Advisory Board, a parent of a consumer living in the community, and a parent of a resident in the Sonoma Developmental Center.

Summary of All Focus Groups, Parents Meetings, Interviews and Written Submissions

All of the information used to prepare the final report is summarized in two tables. The summary includes the 90 appendices included in the draft report, an interview summary from a parent of a consumer who formerly resided in a developmental center that was received too late to be included in the draft report, and five appendices prepared after the meeting of the Advisory Committee. Table 1 lists the focus groups, parents groups, interviews and written submissions that relate to the developmental centers and developmental center areas. Table 2 lists all other focus groups, interviews, and written submissions.

Table 1
Focus Groups, Parents Groups, Interviews and Written Submissions that Relate to Developmental Center Areas

	Agnews	Fairview	Lanterman	Porterville	Sonoma	Appendices
People's First Groups in the developmental centers	1	1	1	1	2	**6**
People's First Groups and consumer groups in the community	1		1	1	1	**4**
Developmental center parent groups	1	1	1	1	1	**5**
Parent of a developmental center resident					1	**1**
Governor's Advisory Boards	1		1	1	1	**4**

Table 1 **Focus Groups, Parents Groups, Interviews and Written Submissions that Relate to Developmental Center Areas**	**Agnews**	**Fairview**	**Lanterman**	**Porterville**	**Sonoma**	**Appendices**
Service provider groups	1	1	1	1	1	**5**
Developmental center executive staff	1		1			**2**
Regional Projects	1		1			**2**
Area Board VII Standing Committee on Agnews	1		1			**1**
Total	**8**	**3**	**8**	**6**	**7**	**30**

Table 2 **Focus Groups, Interviews and Written Submissions**	**Appendices**
ARC Executive Director	.5[1]
Area Board IV, VII, IX, X, XI and XIII Executive Directors and various staff	6
Area Board V Board of Directors	1
Area Board V Executive Director, Alameda DD Council Coordinator and Contra Costa County DD Council Executive Director	1
Association of Regional Center Agencies	1
California Alliance of Inclusive Communities, President, Treasurer and 2 Members; Vice President	2
California Association for the Retarded, Executive Director and CAR Member	1
California Association of Health Facilities, Director Special Programs and Managed Care	1
California Rehabilitation Association, Vice President for Government Affairs	1
CASA, Inc., President	1
CASH/PCR Consultant, Board Meeting Notes and Immediate Past President	3
Department of Health Services, Chief Operations Management and Policy Section	1

Table 2 Focus Groups, Interviews and Written Submissions	Appendices
Department of Social Services Community Care Licensing, Deputy Director and Policy Bureau Chief	1
Family members of former developmental center residents now living in the community (7 family members)	7
Former developmental center resident now living in the community	1
Independent Options, Executive Director	1
LA Autism Society	1
Mayor Pro-Tem City of Diamond Bar	1
Organization of Area Boards Executive Director and Staff Counsel	1
Peoples First of California	1
Protection & Advocacy, Inc., Senior Attorney and Staff Attorney	1
Regional center Executive Directors and various staff: Alta, Central Valley, East Bay, Eastern Los Angeles, Frank D. Lanterman, Golden Gate, Harbor, Inland, Kern, North Bay, North Los Angeles County, Orange County, Redwood Coast, San Andreas, San Diego, San Gabriel/Pomona, Tri-Counties, Valley Mountain, and Westside Regional Centers	19
John R. Shea, PhD	1
State DD Council Chairperson and Executive Director	2
Statewide Regional Center Community Services Directors	1
The Oaks Group, President	1
UCP Legislative Director	.5[1]
Total	**60**
[1]The ARC and UCP interview was conducted jointly and is presented as one appendix.	

Organization of Report

Introduction

People in the system were very generous in sharing their expertise and opinions on developmental center options. There are many excellent and innovative ideas. The information provides a basis for developing responses to the Trailer Bill questions and

to provide direction to planning for the future of developmental center services. The flow of the report follows the questionnaire and the format of the appendices.

Source of Information in the Report

The bulk of the report summarizes data from the 80 focus groups, developmental center parent groups, interviews and written submissions. The specialized interviews with other state departments (2), families of former developmental center residents (7) and one consumer who was a former resident of a developmental center did not ask the same questions. The information from these 10 people is presented throughout the report.

All of the information in the report is based on information provided by people who gave input to the study. The terms “people” and “participants” are used interchangeably throughout the report and refer only to those individuals who gave input. All references in the report to comments made by consumers who reside in developmental centers are based on information that was obtained during focus groups with People First groups in the five developmental centers.

The term “community” is used in this report to identify people, groups and organizations whose primary focus is on those consumers who reside in the community. It does not include people, groups or organizations whose primary focus in on those consumers who reside in developmental centers.

The term “safety net” is used to describe the role of DDS as the provider of last resort. DDS is the only provider of service who is obligated to provide services. Service providers in the community have the option of refusing to serve consumers. Since the state is the provider of last resort in the current system, it provides a safety net for the community based system.

Organization

Values

The report begins with a discussion of core values. The values were identified by participants, as those things that must be present in restructured state services. A suggestion is made in the final section of the report to use the values as an evaluation tool for the efficacy of the various service models. The values that were identified by participants fall into six categories: stability, values related to consumers, values related to staff, values related to service and support resources, values that relate to quality, and the role of the state in the service delivery system.

Principles

The next section is a brief discussion of comments that were made by the participants regarding the principles that were presented to and accepted by the Advisory Committee. People were asked to comment on the principles in part to see if the

developmental center options study was on the right track. While there is support for the principles, there were also issues and questions that came up about all of them.

Planning Structure

The planning section presents examples of planning structures that were mentioned by participants in five interviews. The questions asked about planning were related to who should be involved and what are the issues. There was not a specific question regarding how the planning should be structured.

Major themes/issues

Major themes are issues that concerned people and that need to be addressed when any restructuring plan is put forward. Five major themes/issues emerged in the discussions in the focus groups, interviews and developmental center parents group . The themes are: the creation of a unitary system; uncertainty about the relationships between the community service delivery system and the state operated system; what groups will be served by the state in the future; quality assurance, and how state employees and resources will be transitioned into the community.

Options

This section presents the participants comments and suggestions about service options. It includes an identification of services that people feel are important for the state to provide, fund or oversee in the community.

Trailer Bill questions

The final section discusses a method to evaluate the options in accordance with the criteria in the Trailer Bill.

Summary of Findings

Values

Participants felt that stability is an important value in services and supports and that stability is a key component of quality. People generally agree that quality begins at the direct care staff level. People value staff that is qualified, trained, stable (low turnover), fairly compensated and compassionate. Families and consumers want services they can rely on and that are open, accessible, safe, welcoming, and well monitored. Services should have standards, be vested in quality, have clear lines of accountability, and have ongoing staff training and supervision. Consumers want a full life that includes freedom, activities, work, friendships and other relationships.

People want the principles and values of the Lanterman Act to be the principles and values of the whole community system, regardless of who is responsible for delivering the services. If the state is going to operate services in the community those services must be a part of the community and not separate “mini institutions”. There was

consensus that DDS is the safety net for the system and will continue to play that role for some groups of consumers.

Major Themes/Issues

- People want a unified system in the community. There is great concern that state operated services in the community will result in a two-tiered system where there is not equity in access to resources and where consumers with similar needs get a different kind and level of service based solely on their current residence. Concern was expressed that a two-tier system would only serve to destabilize the community system. There was discussion on what the system role of DDS should be. Should the role be limited or expanded to areas that would strengthen the entire community system, i.e., training, expanding scarce resources such as specialized equipment engineering and maintenance, etc?

- A second theme is concern about relationships between the community operated and the state operated services. People want to know how the system will operate. Will there be the same standards? Will state operated services operate under the same licensure and regulations as community operated services? Who will monitor the services? Who will be responsible for placement, service coordination, and quality assurance? How will consumers move in and out of state operated services?

- A third theme is related to defining the groups that the state will serve. There is consensus that the state should serve the forensic population, but the population needs to be better defined. If other groups are to be served, people thought that they need to be identified. Another issue is who will make the decision as to whether the consumer meets the criteria for state operated services.

- The fourth theme is quality assurance for services and supports. Quality assurance was identified as a need in the system. People feel that the current quality assurance efforts are not sufficient to assure quality. People felt that the same quality assurance system should apply to both state and private services. The components of a quality assurance system include licensure, regulation, standards, best practice, training, and monitoring, including unannounced visits.

- The fifth theme concerns how state employees and resources will be transitioned into the community. There is consensus that moving direct care staff from developmental center settings to the community will require training and a period of transition. Moving developmental center resources into the community is considered to be a good idea. People were enthused about having access to resources that are hard to find in the community, but there was recognition that it will be difficult to make the services available throughout the state. The discussion about how to move scarce resources into the community included some excellent suggestions. For example, traveling assessment teams, telemedicine, and apprenticeship programs were suggested. Placement of responsibility for managing the resources was also discussed. Some suggest that they be attached to regional center.

What Was Learned

The information that is contained in the sections that follow was obtained from people who participated in the developmental center options study. The use of the terms "people" and "participants" are used interchangeably and relate to those individuals who gave input to the study.

Values Identified by People During Focus Groups and Interviews

The focus group and interview discussions about developmental center options began with two questions about values. The first question asked what values should be present in future operated state services. The purpose of the question was to learn what the participants in the focus groups and interviews valued about state operated services as they are now provided. In other words, what aspects of state operated service are so important that care must be taken to preserve them in any future configuration?

The second question asked whether there are values that should be enhanced in future services. The purpose of the question was to find out what the participants in the focus groups and interviews thought should be added to or emphasized in the services as they are restructured. Change always provides an opportunity to do things better or differently. In the context of change, how should the values that underlie the service system change?

<u>Values identified by people during focus groups and interviews about what should be preserved in current state operated services</u>

People's responses to the first question fall into six categories: stability; values that relate to consumers and families; values that relate to staff; values that related to services and supports; values that relate to quality; and the role that state operated services plays in support of the total service delivery system.

Stability

Stability is described in one interview as "the anchor point of the system". It is the value that is used most often to describe what is important about living arrangements, services and supports. Stability is specifically cited as a value in over half of the appendices. Most of the focus groups, parents meetings and interviews included references to and discussion of the importance of stability in services, supports, staff and living arrangements. There is consensus that stability is an essential component of quality.

Values that relate to families and consumers

For the purposes of this discussion, values that relate to families and consumers are those things that establish connectedness and affect the quality of the day-to-day lives of people. The values in this category are values that underlie service delivery and are often a part of the living environment or are exhibited in attitudes and relationships.

Consumers who live in developmental centers identified values that fall into this category as being important to them.

- Participants identified values associated with living environment in a number of areas including safety and freedom from abuse and exploitation; atmosphere of acceptance; freedom of movement; accommodations for people to practice their religious beliefs; quality of life; land dedicated to use for developmental disabilities; and, in Porterville, the geographic location and acceptance by the surrounding community. Developmental center consumers identified acceptance; safety; access to services; belongings; polling place; food; freedom of movement; and jobs and money as values.

- People identified attitudinal values that include client centeredness; dignity; respect; civility; promotion of independence; a sense of well being; respect for rights; Area Board advocacy for people who do not have family or conservators; inclusiveness; and self-determination. Developmental center People's First Groups identified independence; handling their own money; freedom; and rights.

- They cited relationship values as including communication between staff and consumers and families; family access to evaluations and records; the ability of families to visit whenever they wish (with or without notice); access to group activities; access to vocational/recreational activities; and continued involvement of families, advocates and conservators in the developmental center. Developmental center People's First Groups identified family and friends; parties and other social activities; sports and other recreational opportunities; and staff.

Values that relate to staff

A second area of consensus among the participants is the importance of qualified, trained, well-compensated, caring, compassionate and stable staff. One or more values related to staff were included in over half of the discussions. It is clear that people in the system agree that quality begins with the interaction between direct care staff and consumers.

Values that relate to services and supports

Participants placed importance on access to specialists, needed supports, adaptive equipment, and ancillary services. Access, availability, consistency, breadth, and permanence were identified as the characteristics of quality services and supports. Access is particularly important. There was a lot of discussion in the focus groups, parents groups and interviews about the difficulties in obtaining specialized medical and dental care in the community as contrasted with the developmental centers. Consumers also mentioned their doctors, dentists and therapists as being important to them.

Values that relate to maintaining quality

Most of the remaining values cited by people are related to maintaining quality through oversight, licensure, quality assurance monitoring and fixing accountability. Families are very definite that quality assurance must include unannounced visits. There are six references to long-term stability of funding as a component of quality.

Role that state operated services plays in support of the total delivery system

Provider of last resort is the only system role that participants identified in the values section of the discussion. As the provider of last resort, the developmental centers are the safety net for the community system. Almost all of the responses were from the community. The importance of the role is emphasized in other parts of the discussion. It is mentioned frequently in the identification of planning issues and in discussions of the future role for the state. Those discussions also suggest that the role of the state will change and possibly expand in a restructured system.

Values identified by people during focus groups and interviews about what should be added, emphasized or changed in restructured services and supports

There is more diversity in the suggestions for additional or changed values in the restructured service system. The diversity in the suggestions mirrors the planning issues and questions and concerns about restructuring. The suggested values fall into three groups: values that relate to the system; values that relate to the consumer; and values that relate to service options.

Additional, new or changed values that relate to the system

The enhanced values that relate to the system are directed at transitioning the system away from the traditional bifurcated structure of state and community operated services toward a more community based service delivery system. Part of the diversity found in the enhanced values is associated with the details of integrating state operated services into a fully developed community operated system. The diversity also mirrors the diversity of opinion among the stakeholders in the system. What is clear from the values is that there is an expectation that the state operated services will be in and of the community. The community system now operates under the principles and values of the Lanterman Act. There is an expectation that any new state operated services in the community will adhere to those principles and values.

People stated that:

- The Lanterman Act defines the values for the whole system
- There should be a single unified budget and coordinated system of privately operated and state operated services
- Focus of system should be consumers and families; and foster leadership; advocate freedom and responsibilities; promote partnerships; promote interagency collaboration; promote health and safety; promote equal opportunity; and diversity.

- The system should be stable, flexible, responsive, culturally sensitive, promote technology applications and innovation.

- State options must be in and a part of the community; resources available for developmental center and community consumers; there should be state owned and operated services; and the state should consider outsourcing state services to community.

- Presence of state operated a necessity.

- Staff should be skilled, community trained and well paid; promote professionalism; and cultivate and retain expertise.

- Reliable quality assurance to include regulation and licensing of all facilities; state owned and operated done to standards (including security, safety, medical standards and best practice); fixes accountability; best practices for all providers; uniform standards; and includes unannounced access.

- Safety net in the community; to include mental health.

Values that relate to the consumer

There is an expectation that consumers who move into the community, regardless of the provider of services will have the same rights as other consumers in the community. The emphasis is on having a full life including relationships.

- People with disabilities live and are active, full participants in the community.

- Their civil and citizens rights and privacy are honored.

- Consumers should be respected; exercise choice; be decision makers; have control over their lives; be empowered; have access to advocacy; enjoy quality of life; have satisfaction; and independence.

- Current relationships (i.e., friendships) should be maintained in the community.

- Relevant and useful information should follow consumer into community; with annual and semi-annual progress reviews.

Other things that participants mentioned under additional, new or changed, values that relate to service planning, and specific services and support options

People mentioned various characteristics related to service planning and service options during the discussion of additional, new or changed values. These are also diverse and range from those who envision a system with options that are mix of the traditional services in the system to those who begin with the premise that state operated services should be restricted to those people who cannot be served in the community because of their dangerous propensities.

People suggested:

- Service planning
  - Person centered planning and service development and IPP is the guiding document.
  - Move away from concept of services to a concept of continuing support.
  - Service provision is not burdened by funding restrictions.
  - Open to new individualized options.
  - Placement based on human issues, not philosophy.
- Residential
  - Community is the preferred location; option to live in home community
  - Quality safe and adequately funded community living arrangements designed to meet the needs; services planned and implemented to meet needs.
  - Family like settings.
  - Developmental center residents to have residential services provided by state employees as long as the person or family prefers the option.
  - Seamless system where people who need developmental center services should have them; live in setting that best fits needs including congregate.
  - An “Agnews” type of option that includes the same kinds community support, social aspects, and family/other contact as currently exists at Agnews Developmental Center.
  - Mimic services that are provided by the developmental centers.
- Services and supports
  - Access to all needed supports and services including medical and other specialists
  - Supports and services should be stable, have an array of viable options; foster freedom and mobility.
  - Wider array of work and social activities
  - Continuity of care and life (no change or limited change); services should only be enhanced.
  - Recognize dignity of risk through least restrictive supports
  - Capitalize on successful models.

Values identified by parents of former residents of developmental centers

Six families of former residents of developmental centers were asked questions regarding what had made the transition from the developmental center successful. Their sons and daughters had been long-term residents of the developmental centers.

Three had lived in developmental centers for more than 30 years. What the parents felt was the most important factors were service and support options that changed as the needs of their family member changed, no loss of service as a result of the move, and having someone with whom they and their family member had a relationship who could assist them in finding the options. In the case of these families, the assistance came from a regional center service coordinator.

Principles

People were asked to comment on the five principles that were presented to and accepted by the Advisory Committee at its June 2000 meeting. The original intent of the principles was to provide objectives for the study. Some 15 organizations have gone on public record as supporting the principles. Overall 35 of the 73 focus groups, parents meetings and interviews stated support for one or more of the principles. All of the interviews, parents meetings and focus groups commented on or had questions about the principles. In part, the lack of a detailed explanation of the rationale behind the principles generated the comments and questions.

No major capital outlays to rebuild developmental centers

Community members tended to agree with this principle. The parents group meetings and others raised questions about how this principle was reached. The presentation of information appears to link the principle to the Vanir estimate for rebuilding developmental centers. There is conjecture that the cost of developing four person homes in the community for 3800 people may exceed the cost of rebuilding developmental centers.

Homes limited to four persons or less

This is the most controversial principle. Some, who fully support the principle, cautioned that it should not act as a limitation to consider other options such as supported living nor should it result in mini institutions in the community. People pointed out the conflict between the language in the Trailer Bill that calls for consideration of all options and the presentation of a principle that places a numeric limitation on the size of any options. Others questioned the economic viability of the option, particularly for ICF/MR facilities. Suspicions were raised that the adoption of a four-person home was an attempt to circumvent licensing requirements.

Capture and extend developmental center resources in the community

The concept of extending developmental center resources in the community received considerable support. It is generally acknowledged that developmental centers have expertise that is difficult to access in the community. There is also consensus that access to the services would strengthen the community. There are suggestions related to the use of innovative methods to extend the services. However, there is not consensus on who should be responsible for managing the resources. Regional centers would like to see the resources become a part of the community service system. There is also concern about limiting the recipients to current developmental center residents.

Leverage the developmental center land to create new resources

Discussion on leveraging developmental center land fell into two general categories. Some people support this principle with the caveat that the gains realized from the land be dedicated to the developmental disabilities system. There was not a lot of support among the developmental center parents groups for leveraging the land. They prefer to keep and use the land.

Conduct highly individualized personal assessments and resource development before the move to the community

This is the most universally accepted principle. The comments tend to fall into four categories. There are suggestions that this should be the first principle since it drives the development of options. There are comments that this is the law and should be going on now. There is a concern raised that the highly individualized personal assessments and resource development should not be limited to residents of developmental centers but should available to consumers in the community. The final category includes many suggestions on how to improve individualized planning.

Planning Structure

Two questions were asked about the planning process, who should be involved and what should be done? The purpose of the questions was to obtain assistance from the stakeholders to construct the planning process and frame the major issues and questions. During the course of the data collection, people gave contradictory cautionary advice about the planning process. Some cautioned that the planning process should not be allowed to drag on and delay implementation. Others suggested that sufficient time be allocated to develop a complete plan. The message is that people recognize that the plan to develop and move services into the community for developmental center residents will take time to implement and that implementation should neither be unnecessarily delayed nor precipitously started.

There are basically three steps in any planning process: developing an objective, identifying the major issues to be considered and then settling on planning process to get there. The planning process includes defining a structure and deciding who should participate.

Restructuring state operated services is the objective for this effort. The data collection effort that is described in this report identifies the major issues to be considered. Consensus has been reached that all stakeholders should be involved in the process. A long list of possible participants has been identified, including consumers, families, DDS executive staff, developmental center staff, advocacy organizations, service providers, constituency organizations, regional centers, representatives from other state departments, and local community and public organizations. What is left is to decide on a planning structure.

People were not specifically asked to comment on structure. Fortunately, there are several good suggestions for planning structures in the appendices. The suggestions include four defined structures as well as a thoughtful discussion about a fifth process.

These are briefly described below. A more complete description has been excerpted from the appendices and is presented in Attachment B. The purpose of presenting the information is to provide a more complete description of the various ways the planning process could go forward. They are not recommendations.

- There is a bottom to top structure that suggests that principles to guide the planning be developed and implemented starting with a comprehensive assessment of persons who reside in developmental centers that includes a planning meeting with the person. Service design and development will be based on individualized assessments and completed on a regional basis. Partnerships between the state, regional centers, providers, consumers and their families can only be accomplished locally. The role of the state is to support their efforts.

- The second structure is a regionalized structure that starts with ideas and momentum generated from the grassroots of the system. The planning structure is decentralized and is regional center or multi-regional center in nature. Regional centers would develop plans individually that would be integrated into the range of resource needs within their local communities. The coordinated proposal would be submitted to DDS. The regional centers would negotiate with the state for funding, resources and the ultimate objectives of the plan. The plan for the region/regions would include the role of the state, both as a direct service provider, resource developer, and consultation. The role of the state would differ from plan to plan. Some regions may wish the state to take a more direct role in providing services and resource development than others.

- The third structure is a local planning area structure where the state assumes a leadership role in defining criteria for the plan with regional planning groups empowered to actually implement portions of their local plans. The planning groups could be based on what stakeholders and others felt were compatible planning areas. The master plan could be developed through contract. The plans would address local needs and resources.

- A fourth structure is a pragmatic approach that involves all of the stakeholders. The process is structured to make it manageable. It envisions DDS meeting with the leadership of the various stakeholder groups and Legislature to agree upon a small representative group that would do the actual planning. The first step in the process is development of a clearly stated objective that includes a list of nonnegotiable decisions. The planning group is not being asked to help make strategic decisions. They are being asked to help with the tactical questions and issues associated with implementing the objective. The state can also define areas of flexibility within the process, but there must be a specific end date. Key indicators of success must be clearly defined and monitored.

- The fifth process involves multi-tasking instead of linear planning and implementation. It begins with a decision that planning and implementation can move forward simultaneously. Within the stated objective of the planning process there are a number of things that have been clearly defined as needing to be done regardless of what final decisions are made in the plan. For example, if the objective

is to identify needs though a comprehensive individualized planning process that includes people from the community, we know that the current process needs to be reviewed and brought up to date, people need to be trained in how to do the planning, and outside people and groups need to be identified and trained. All of this effort can move ahead while the larger planning effort is underway.

Major Themes/Issues

Major themes/issues are those things that participants felt were of particular concern and should be addressed when any restructuring plan is put forward. The discussion of planning issues and concerns produced five major themes. The themes are the central planning questions and issues to be addressed as a part of restructuring. The themes are: creation of a unified system; relationships between the community operated and state operated services; definition of what groups the state will serve; quality assurance; and how state employees and resources will be transitioned into the community.

Creation of a unified system

Restructuring state operated services will result in a fundamental change in the structure of the service delivery system. In the current system there is a clear bifurcation between state and community operated services. The state services are provided at fixed points that are segregated from the community system. While there is sharing of resources in some parts of the state, the systems operate under different circumstances. There is great concern that when state operated services are moved into the community that the system will continue to operate as a bifurcated two tier system in the community. It is feared that the state operated system will have access to greater resources that will result in a higher quality of services. The resources include access to specialists, adaptive equipment, and ancillary services that are not generally available in the community as well as the ability to pay higher salaries and benefits to the staff. Access to the state services is also an issue. If the state operated services are available only to current residents of the developmental centers, the result will be unequal access to services by consumers with similar needs based solely on their place of residence at the time of restructuring.

Concern has been expressed that overlaying a community system that is already stretched to its limit, with a better funded and separate system of services will cause disruption. The result will be to further weaken the community system. There are recommendations in the appendices to create a unified system of services such that consumers and families will have access to the same quality and level of services based upon individual need regardless of who delivers the services.

Relationships between the community operated and state operated services

The second theme is the relationship between community operated and state operated services. The relationship is well defined under the current system. It is not at all clear for the future system. The crux of the issue lies in the definition of the state role in the restructured system. The issue was raised by almost everyone. The following summarizes some of the questions.

- Will the role be extended to include a direct role in providing hard to find services in the community? The community is eager to have greater access to hard to find services and there is support from the developmental center families that the services should be made available regardless of what happens to restructuring.. There are those who would like for the state to become the provider of last resort for all services. Many suggest that the state take a lead role and be responsible for extending the availability of the resources through the use of technology and innovation. Others suggest extending the services through contracts or partnerships with medical and dental schools. Some suggest a training role for the state and the possibility of the state establishing a training academy. There is also a suggestion to give the resources to the community.

- How will the regional resource centers operate? Will they compete with regional centers? There is consensus that the services that would be available in the centers would be valuable to the community. Access is an issue. Also, there is not consensus on who should manage them. Community people want universal access to the resources from the outset. They do not want to have to wait to access them at some future date. There are those who do not want the resources to be managed by regional centers. Others think that the regional centers are given the responsibility in the Lanterman Act to be local point of contact for services and support so that it is only logical to fold the services in the regional centers.

- How will the state operated services in the community relate to the regional center? Who will do placement? Who will do service coordination? This is a point of disagreement among the community and the developmental center families. The community is very committed to having a unified system. In that system the community would be responsible for providing service coordination and participating in placement activities. The developmental center families want the state to continue to play these roles. The issue is further complicated by the need to define how people get placed in the state operated services.

- Who is responsible for quality assurance, monitoring and oversight? How about licensure and regulations? Will the rules be the same for all services in the community regardless of providers? Will there be separate or coordinated resource development? This issue is directly related to having a unified or two-tiered system. There are recommendations to fold the state operated services into the community system where everyone would operate under the same rules and regulations and suffer the same consequences. There are other recommendations to maintain the current standards and licensure for the state operated services as exist in the developmental center system.

<u>Defining populations to be served by the state</u>

The population that is eligible for state operated services needs to be clearly defined. There are those who think that the population should include only those people who cannot be served in the community because of dangerous propensities. This group believes that everyone else should be served in the community with community

resources. There are others who have suggested that there may be a greater number of people who should be served by the state. In order to go forward, and to avoid confusion in the future it is necessary for the system to define who is eligible for state operated services, how the determination will be made, and how consumers gain entrance to state services.

Another part of the issue relates to the "forensic" population. Suggestions were made by a number of people that since this is not a homogeneous group that the state needs to do extensive individualized assessments and reviews to determine who is truly dangerous to the community.

Quality assurance

The issues related to quality assurance include the concern that state operated four - person homes in the community be licensed and regulated; that all community based services operate under the same standards, rules and regulations; and that an effective quality assurance program is not in place in the community. The concern about licensure of four person homes in the community is based upon a belief that the four-person principle was adopted to satisfy the HCFA definition of an institution and to avoid having licensure for the homes. Families were particularly concerned that their family members would be in unlicensed and unregulated living arrangements. They want the homes to be licensed in the same way that developmental centers are licensed and regulated.

The second concern comes from the community. They want assurances that the state operated services will be subject to the same standards, rules and regulations as the community including the same consequences for failing to meet the standards, rules and regulations.

The third concern is more general. Effective quality assurance is an essential component of service delivery. People do not believe that the current quality system is comprehensive or effective. Of particular concern is the lack of unannounced visits. There are others who say that monitoring isn't enough, that the system has to address more pervasive issues such as inadequate funding for salaries and benefits to get the quality it wants.

The background interviews with DHS and DSS touch on this issue. Departmental representatives were asked to comment on the issues that they would see in placing developmental center residents with severe behavior challenges or major healthcare needs into small community-based homes. Both departments commented on the impact on their ability to monitor within existing staff resources. DSS said that from their perspective the homes would have to be licensed by DSS or DHS.

Transitioning state employees and resources into the community

If restructuring occurs state employees and resources will have to be transitioned into the community. Many issues were raised about the transition. The issues extend from the lack of experience the state has in operating small facilities in the community to how

to make the developmental center services available throughout the state. The issues are listed below.

- There are questions as to whether the state should provide any direct services in the community. The options that are being suggested are options that the community has in place. Some suggested that the state could provide small business loans to state staff to encourage them to become service providers in the community.

- It was suggested that the state does not have a lot of experience in managing small facilities in the community. At present, the expertise on how to operate in the community lies in the community.

- The principles and service options make reference to extending developmental center services into the community via "regional resource centers". This principle received a lot of support. The questions arose around how best to spread the services throughout the state and who should manage the resources. Many people suggested the use of technology, mobile teams, apprentice programs, school affiliations, etc. It was also suggested that the best way to manage the resources and make them more generally available is to fold them into the existing community system.

- Transitioning residential and day services into the community is another issue. People expressed concern that the four person homes not become mini institutions. They stated that when the services are moved into the community, that the services have to be provided under the community values and rules. The homes have to be part of the community, not just in the community. There was also a suggestion that the residential options be spread throughout the state and not clustered around developmental centers.

- A related issue is transitioning state employees into the community. There was a lot of discussion about the need to provide community based training to state employees prior to the move into the community. People have pointed out that the job requirements in the community are very different from the job requirements in the developmental center. In a small community based home the staff is required to be more full service than in a large developmental center environment. They have to exercise more independent decision-making and take care of many things that are taken care of by others (dietary, laundry, etc.) in the large institution. It is suggested that a very well thought out and constructed training plan is needed.

Options

Gathering opinions and suggestions about options was a major focus of the project. People were provided with a preliminary list of options for comment (Attachment C). They were also encouraged to make suggestions for additional service options.

Residential

Suggestions made by participants

- There was general support for a state owned option. Ownership of the home would satisfy the need for long term stability of living arrangement. It was viewed by some as being more important than the actual operation of the home by the state.
- A variation of the state owned option was a state owned privately operated option. The rationale was the same with regard to stability.
- Foster Home Agencies for children was suggested as a good option.
- ICF/MR option
- There should not be a bias toward developing only facilities.
- Develop model programs.
- Communal villages
- Housing coordination to develop opportunities for low cost housing throughout the state.
- Place homes in rural like settings.
- A continuum of care that includes congregate care.
- Services should be brought to the place the person lives, his/her home.
- Developmental center should be an option.
- Villages
- Homes located near developmental centers.
- Homes not located around developmental centers.
- Skilled nursing facility for people with behavior challenges.
- State contract with community for direct care staff supervised by Psych Techs with staff training in the community. This option would integrate the community with the state.

Participant comments about options on the list

- *State staffed homes in the community for four or fewer people where the home is leased.* There was concern about the stability of a lease. There was a suggestion to have the foundations connected to regional centers be the nonprofit agency who owns the land.

- *State provides special supports to privately owned and operated homes*. The concern about the stability was raised in this option as well. There were also some who felt the state would be better served by augmenting rates to community providers to allow them to serve the consumers without state involvement.

- *Person lives with family; state provides services.* The families of developmental center residents did not feel that this was a viable option for them because of their age and the age of their family member. They did think that it might be a good option for families who needed help to keep their family member from going into the developmental center. People in the community questioned why the state couldn't just provide more funding for the services.

- *Supported living* received support and some very specific suggestions about how to make it work. One suggestion was to help state employees start supported living agencies. There were several suggestions about the need to be able to augment the rent for consumers and to remove the cap on expenditures.
- *Host adult family homes for one or two consumers received support*, but it was pointed out that there had not been wide spread development of this option in the community. Part of the problem is the restrictions on current state employees being able to operate the homes.

- *Self-determination* received support. One comment was made that the state would have to deal with the issues related to developing resources to meet some of the needs.

Day activities

Suggestions made by participants

- Develop a MediCal funded program.
- Develop an option where the person could plan his or her own day activities.
- CARF certified work options with consumer wages based on prevailing wage.

Participants comments about options on the list

- *Options to use existing day activity program was considered a viable option if there was the ability to augment staff resources*. There was concern expressed about the option to send a residential staff person along. Suggestions included removing barriers to participation by people with health issues in existing day program.
- *State provides day program* did not receive a lot of comments.
- *Options where residences would provide the day program* were not considered good ideas. It was felt that the consumers needed more variety in their lives.
- *Option where one residence develops the day activity program* was not considered to be a viable option. In addition to the concern expressed above, there were concerns expressed about the loss of an extra set of eyes to monitor for abuse and neglect. It was suggested that if the person could not leave the residence for a day activity that an outside agency be brought in to conduct the program.

Other services

Suggestions made by participants

- A place in the community that can supervise and control medications, including weaning people off of medications.
- Clinical and ancillary services need to be expanded.
- Mental health services.
- Need to address the nursing shortage.
- Short term treatment and rehabilitation facility for behaviors, mental health or other challenges where people could get extended treatment.
- Assuring advocacy services are available throughout the state.
- State operates a training academy that could bring together nationwide experts to develop curricula and to provide follow-up mentoring.
- Psychiatric centers to work with adults.
- Making the community the safety net by developing and funding resources in the community to support maintaining consumers in their desired living arrangements.
- Understanding why adolescents and others exhibit severe behaviors. Highly skilled and respected groups should be recruited to participate in multi disciplinary assessment teams in the north and south to act as a resource in figuring out the best approach to take with the consumers.

Participants comments about other options

- *Regional resource centers* were considered to be a good idea but there was strong support for the resources to be used to strengthen the community and not be a separate system from the community. It was suggested that the resource centers be attached to regional centers. It was also suggested that the state be the provider of last resort.
- *Crisis homes, intervention teams and respite beds* were considered to be good ideas but there were suggestions that the homes and respite beds be available to children and adults.

Participants comments about an option to build on developmental center land

The families of developmental center residents were in favor of this option. Community people were generally opposed to this idea.

Trailer Bill Language

The Developmental Center Options Study was undertaken to gather information on options to serve as a basis for the report to the Legislature that is mandated by the Trailer Bill language. This report and the appendices present a wide range of opinions

about restructuring developmental center services. The information is useful in responding to the Trailer Bill requirement for evaluating the options. The Trailer Bill has three evaluation criteria: appropriateness in meeting consumers' needs; compliance with requirements of federal and state laws; and efficient use of state and federal funds.

Appropriateness in meeting consumers' needs

None of the options mentioned in the Trailer Bill, the preliminary list of options, or in the suggestions made during the course of information gathering is a new and untried option. Thus, all of the options can, in theory, meet consumers' needs and the requirements of federal and state laws. There were no issues regarding legality in the background interviews with DHS and DSS except for locked facilities.

It is important to remember that what is changing in restructuring is not the option itself, but the operator of the option.

Appropriateness in accordance with system values

Meeting a consumer need doesn't necessarily mean that the option is appropriate within the values of the system. For example, the day program option where day activities were provided by the residence was deemed inappropriate because it took away one method that the system uses to monitor for abuse.

Appropriateness of future options can best be determined by laying the suggested option against the values that have been identified for future state operated services. For example, how does the option assure stability?

The values identified in the report include stability; the Lanterman Act values; quality; trained compassionate staff; relationships; client centeredness; individualized services and supports; access to needed supports; quality assurance; consistency; continuity; etc.

Appropriateness in meeting the needs of an individual

The highly individualized assessment and planning principle was universally embraced. This is the place where an environment is constructed to meet the needs of the individual. Options will need to be developed or identified that meet the needs of the consumer.

Efficient use of state and federal funds

Efficient use of state and federal funds is the final criterion mentioned in the Trailer Bill. The cost benefit associated with the criterion is underway.

Planning And Achieving Person-Centered Environments For People With Developmental Disabilities

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February 14, 2001

Executive Summary

People with developmental disabilities who choose to live in the community will require permanent-housing that meets their physical needs and satisfies their desires. It is possible, through the careful planning and design of their living environments, to eliminate obstacles, reduce restrictions and increase choice in their lives. This profound shift empowers individuals with developmental disabilities and fundamentally changes their relationships with others. It can be done cost effectively, and is best achieved in real homes with domestic character located in active and accepting communities. Successful models of this exist in California and across the nation. Based on a study of these models, techniques and processes are being developed to produce the next generation of integrated housing which will be required in California.

To achieve this goal you must:

1. **Adhere to core values that ensure a desirable outcome:**

   - Build homes which meet public expectations of health, safety, permanence and quality
   - Respond to individual needs and desires
   - Be the place which promotes a real life
   - Become the real home for the residents
   - Be of the neighborhood and connected to the larger community
   - Be a place to live for the foreseeable future

2. **Acquire the specialized knowledge, techniques and solutions required for success:**

   - Develop cost effective prototypes which respond to need and desire
   - Find good neighborhoods
   - Fit in and be a good neighbor

3. **Have a systematic process for planning, development and implementation:**

   - Select compatible individuals, and identify a house type and possible locations
   - Gather information about the people and the place, and adopt a development plan
   - Design and construct the project meeting quality, cost and schedule requirements.

OVERVIEW

In July of 2000, Creative Housing Solutions responded to a request from the California Department of Developmental Services to study community and institutional housing models serving persons with developmental disabilities. The study has focused on developing a plan and process for how to achieve lousing in the community that is a good fit between person, place and support. The premise is that most people with disabilities, when provided with the opportunity, will choose to live in the community and will need housing that meets both their physical needs and their desires.

The framers of the restructuring plan know that the physical environment is a critical factor in creating successful community placements. Recognizing that people with disabilities in California ought to be able to exercise choice in their daily life, to live in a home-like setting and to be part of a supportive community, the challenge is to offer environments where individuals who choose to live outside the institution will have a high likelihood of success. Adapting housing options to the complex circumstance of each person's life and of the community in which they will live is the heart of this challenge. It is also the source of vitality that is often missing in controlled institutional settings.

People with developmental disabilities and their supporters are becoming increasingly aware of their rights. The 1999 Supreme Court decision in the Olmstead Case has empowered consumers as never before to make choices about where they want to live their lives. It is increasingly important throughout the country that states have the ability to provide cost effective living environments in the most integrated settings. A process to guide the planning and design of person-centered environments for people with developmental disabilities is a critical element of the California Department of Developmental Services restructuring effort.

Values that guide the process

National research indicates that success outside the institution is achievable for most individuals with disabilities. Planning and implementation of these environments require a willingness to invest in physical quality, adherence to core values, and a systematic development process.

To be successful, the person-centered environment must:

- meet public expectations of health, safety, permanence and quality
- respond to individual needs and desires
- be the place which promotes a real life
- become the real home of the residents
  be of the neighborhood and connected to the larger community
- be a place to live for the foreseeable future

Values that put people first are key to creating successful living environments. Ultimately it is the people—the residents, family, staff, friends, caseworkers, and neighbors-who

are primary in creating a non-institutional culture. The environment, however, plays a central role in shifting the balance within this culture away from obstacles and restrictions toward choice and participation. Beyond responding to the essential requirements of health and safety, a supportive environment can free a person with disabilities from institutional impediments, allowing them to live a more normal, independent life. Experience has shown that a person-centered environment designed to meet the needs of the individual not only empowers the person with disabilities, but also reduces stress and workload on staff, caseworkers, family and others who are part of that person's life.

One example of how these values can translate to physical results and positive outcomes is a project recently completed for a young girl with autism Anna spent many hours each day in the bathroom in intense water play, a source of tremendous stress on her family and damaging to the physical structure of their house. Based on an evaluation of the space, Anna's desires and her family's needs, a remodel plan was developed to improve the layout and technical performance of the bathroom. Grab bars, impervious materials, heated surfaces, improved lighting, durable fixtures and other elements were introduced. The evaluation of the completed project and its effect on Anna's life shows that she can now do what she clearly enjoys without negative consequences. Safety is improved, damage to the building is minimized and her family experiences significantly less stress and more freedom because they spend less tine doing intensive supervision and cleanup. Anna has exhibited a reduction in behavioral episodes because she experiences more choice, control and independence in her life. Anna's ability to continue to live at home with her family is a substantial return on the investment in physical improvements.

For many people with developmental disabilities, living with family is not realistic, but living in a genuine home rather than an institution is a real possibility. An institutional configuration, with its systems, processes and procedures, regulates the activities and rhythms of life. In a home it is the good relationship between resident and staff within a supportive physical setting that fosters a more natural existence. In a real home the activities of daily life-making meals, doing laundry, relaxing and planning activities-take precedence over institutional protocol. In this setting, positive family-like relationships can replace the traditional client-employee paradigm Staff are empowered to make the right choices, and residents live a more integrated life. This profound and positive shift becomes possible in small group settings, but small size alone does not guarantee success. Houses, for example, which require multiple residents to share a bedroom or where their diets are dictated by a dietitian, prepared remotely and then rethermalized, may be re-creating the institution in the community. Indeed it is possible to create an institution in a house with only one resident.

The environment should support resident access to all domestic activities and encourage integration, while ensuring resident privacy. The office, for example, if too large and separate can result in staff isolation. Accessibility and visibility to kitchens and utility rooms puts people in touch with important activities of daily life. Providing a staff and guest bathroom, on the other hand, reinforces the positive perception that the residents' bathrooms are their own. A separate entrance to the office can allow outside business to occur without invading the home.

Successful community placement depends upon a commitment to quality and to permanence in the living environment Housing must provide a level of support that guarantees the person with developmental disabilities a safe and healthy place to live for the foreseeable future. The buildings must be constructed for longevity and durability to withstand heavy use over a reasonable life cycle. Housing which does not satisfy these basic requirements is not equivalent to the institutional models it replaces and in the long run will fail the consumer and the public. In addition to affecting maintenance and life cycle costs, the quality of the environment affects worker safety and shapes the attitudes of residents, staff and the larger community. Poorly designed or inadequate facilities can result in costly worksite injury claims. Staff can become discouraged trying to meet licensing standards. Poor quality can result in neglect by staff and damage by residents, compounding the negative perception of the housing. Parents and advocates may complain or file legal suits, residents may choose to live elsewhere, and the community's confidence in the program may be diminished. These problems are preventable if housing is done right. Experience has shown that good quality, permanent housing is achievable at reasonable cost using conventional construction techniques.

Cost effective prototypes which respond to need and desire

One of the ongoing challenges is to balance responsiveness to individual's needs with the need of the public sector to efficiently provide housing that is flexible and cost effective. To achieve this balance, research is being done to identify and design prototype models which can support residents in small group settings and can be modified for the individual.

The search for a widely used, readily available and current client information source has led to the Client Development Evaluation Report (CDER). Although the CDER was not originally intended to identify housing and component needs, it has been invaluable in providing data that can suggest environmental responses. The CDER provides information on the history and place of origin of the consumer. It has also helped in the identification of five major housing types corresponding to the CDER disability domain classifications. Housing prototypes are being developed for the following classifications: medically fragile, mobility impaired, behaviorally involved, mentally disordered, or requiring secure settings.

Prototypical home models, design elements, and details are interpreted within an "open system." In other words, the system is responsive to individual needs, modifying or adapting designs or features to meet those needs. A safe and healthy environment that addresses the disability needs of the individual is the first priority. This can be successfully accomplished in a non-institutional setting. The other opportunities and advantages offered in a home-like setting become possible once this essential requirement is met.

Research and experience in institutional and community-based housing environments has enabled the development of cost effective, buildable floor plans, components, fixtures and design elements that comprise a housing type. The information being gathered will prove invaluable both to new developments and to existing residential programs seeking to upgrade or resolve problems. For example, by studying the residences of persons with tendencies to test the

strength and durability of their environment, window components and hardened wall construction are identified that hold up under these conditions. The windows are fitted with 1/4" tempered glass interior panes and 1/8" tempered exterior panes. Walls are backed with plywood and are finished with veneer plaster or in extreme cases with fiberglass reinforced plastic. These components maintain residential character and fit within conventional construction techniques Homes serving persons who sometimes become angry or frustrated and act out in aggressive ways also work better if two separate living areas are available. Specially designed heavy duty pocket doors can provide a physical separation between living areas if needed but disappear into the wall when not, maintaining the real home appearance of the residence.

Finding a good neighborhood and fitting in

The selection of neighborhood and acquisition of property may be the most important and complex choice in the development of a home. A values-driven strategy informed by realities in the field has been found to be the best way to control cost and achieve a good fit in a community. Strategies are being developed for location selection that take into consideration the preferences of consumers and their supporters, assess technical criteria affecting feasibility, development and construction, and evaluate the potential for consumer participation in the community. Multiple factors are at work, including the proximity of family or the existence of other personal relationships; the existence of essential health services, programs for residents and Centers of Excellence; the degree of welcome-ness and the potential for acceptance in the community; and the availability and affordability of property.

In October of 2000, several locations in the Tri-Counties Regional Center area were tested for compatibility with core values and technical criteria. In popular urban areas of the region high costs of living, expensive land and expensive housing are significant obstacles to development. In the more affordable and available rural areas of the region the scarcity of hospitals, qualified health care providers, public transportation and provider programs are serious deficiencies. These outlying areas are more spread out, have fewer amenities and may have harsh climates, raising a concern about consumer safety and isolation.

Suitable places for development were found in these counties. Regional Center staff who could offer local experience and intelligence were invaluable to this search. Suitable locations tend to have neighborhoods of mixed housing type and mixed population which are not over-saturated with supported living arrangements. The crime rate is low and the resident population is socially and economically diverse. Desirable locations tend to be near an accessible and viable downtown, offering employment opportunities, shops, restaurants, thrift stores, movies, open spaces and parks.

Established neighborhoods with mixed housing stock have been found to offer amenities and conditions that favor community placement New or remodeled housing can fit within the varied character of the neighborhood. Local residents tend to be less resistant because there is more social and economic diversity in the population. Stores, home businesses, shops and local parks encourage social interaction. In mixed neighborhoods the potential exists for persons with developmental disabilities to live in a desirable place and participate in the community.

Once a good neighborhood has been found, a positive relationship must be cultivated, and once the residents have moved in the relationship must be sustained. In both design and operation every effort should be made to be a good neighbor. Done skillfully, a group home fits in and is indistinguishable from other houses. Initially, many neighbors feel justified in judging both the home and. its residents. Suspicion, fear, ignorance, Jack of exposure or negative past experience with group homes can fuel a "not in my back yard" attitude. Visits to the property by the future residents and their supporters can allay these fears.

After the home is open, with the exception of persons with uncontrolled screaming behaviors, very few complaints from neighbors involve consumers. Instead, the maintenance of the property and the behavior of the staff are the principal sources of tension. Traffic arid parking problems such as cars left on the street, blocking driveways, or using all available spaces are common sources of complaint Unacceptable noise such as loud music in personal vehicles and loud talking, yelling and arguing late at night is also a major source of frustration and annoyance for neighbors.

An attractive, well-maintained building and landscape shows pride of ownership and contributes to the appearance of the neighborhood. Attention to neighborhood patterns such as fencing, yards, plantings, porches, compatible building forms and local materials can make the home fit in. Investment in a good building, an attractive landscape and ongoing maintenance contributes substantially to positive perceptions and to a sense of belonging.

The process outline

1. Select compatible individuals, and identify a house type and possible locations.

- Use the CEDR and other whole-person assessment information to identify possible residents.
- Investigate consumer origin and identify support systems.
- Select a plan and components that support individual needs and desires of the group.
- Test the conceptual plan against core values and technical criteria:
    - Can it meet health and safety requirements?
    - Does it have potential to meet needs and desires?
    - Does it have potential to be a real home?
    - What are the considerations for aging in place?
- Visit potential locations for the home utilizing local knowledge.
- Test the location against core values
    - Does it satisfy the needs and preferences of the consumers and their supporters?
    - Does it meet technical criteria affecting feasibility, development and construction?
    - Is there potential for involvement in the community?
- Identify the development team.

- If the proposed group is compatible, the building type and site are feasible, and a development team is identified, proceed to the next phase.

2. Gather information about the people and the place. Adopt a development plan.

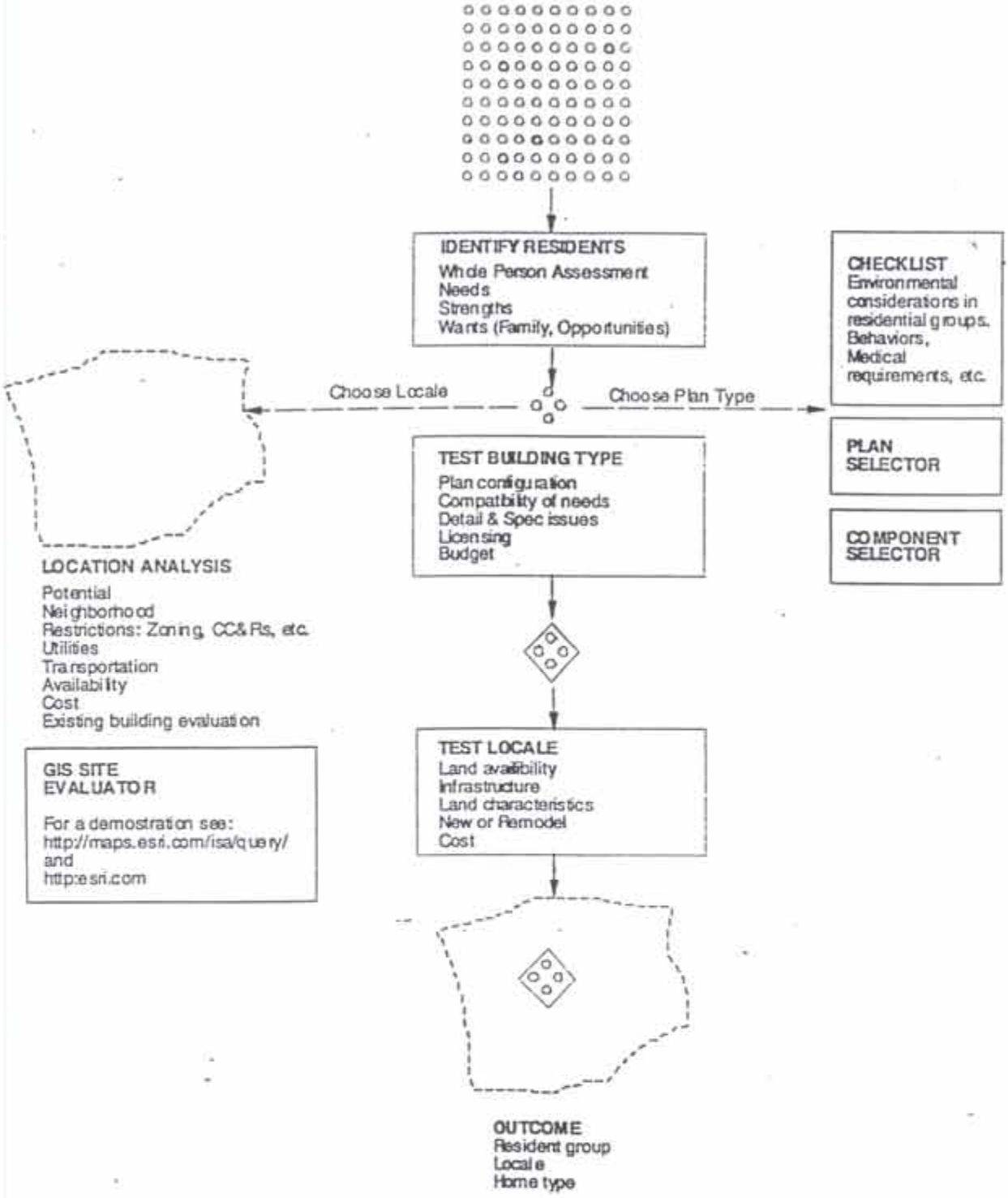
- Analyze individual needs, program requirements and licensing requirements.
- Identify neighborhood.
- Evaluate neighborhood's conformance to values and technical requirements.
- Test plan type, program and available properties.
- Finalize development plan: program, house type, special features, property, budget, schedule, and development team.

3. Design and construct the project

- Refer to design guide to produce schematic site plan, building plan and elevations.
- Conduct preliminary selection of building systems and materials.
- Conduct preliminary check with local planning, building and fire officials.
- Review schematic design and cost estimate with development team.
- Proceed with construction documents: architectural, structural, plumbing, mechanical and landscape.
- Submit for building permit
- Conduct bid process and enter construction agreement with contractor.
- Construct the building
- Move in and then evaluate

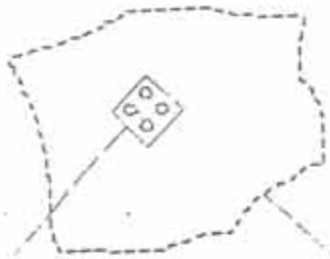
1. RESIDENT SELECTION AND FEASIBILITY

The purpose of this phase is to test the feasibility of a proposed resident group before proceeding with more detailed analysis and project development.



2. ANALYSIS AND DEVELOPMENT

The purpose of this phase is to analyze the specific requirements of individual residents and acquire an appropriate site for the home.



DETAILED PROGRAM ANALYSIS
Individual needs
Program
Licensing

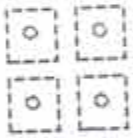
QUESTIONNAIRE

SITE/BUILDING ANALYSIS
Potential
Neighborhood
Restrictions: Zoning, CC&Rs, etc.
Utilities
Transportation
Availability
Cost
Existing building evaluation

CHECKLIST
Criteria for the analysis of group home sites

TEST
Program and Property

SITE ACQUISITION



PROGRAM

OUTCOME

Individual needs assessment
Physical requirements
Property ownership
Development strategy
Budget

PROPERTY

DESIGN AND IMPLEMENTATION STRATEGY

POTENTIAL FOR REPETITION → PROTOTYPE

UNIQUENESS → LOCAL SOLUTION

3. DESIGN AND IMPLENTATION